CHAPTER 12

Serious Illness and Disabilities

Family Challenges and Resilience

> All the world is full of suffering; it is also full of overcoming it.
>
> —HELEN KELLER, *Midstream: My Later Life*

Serious illness and disability pose a myriad of challenges for families, requiring considerable resilience in coping and adaptation. A health crisis can also be experienced as a wake-up call about our lives. It can heighten and alter our sense of priorities, which are too often lost in the helter-skelter demands of daily living. Persistent and recurring conditions can require changes in our patterns of living and reorient our hopes and dreams. This chapter highlights salient issues for a family resilience approach with serious health and mental health challenges.

LEARNING THE ART OF THE POSSIBLE: LESSONS FROM LIFE

Over the life course, serious illness strikes us all; therapists are not immune. Our own experiences with illness and caregiving challenges can teach us many things about resilience. It can also deepen our work with individuals and families who are striving to live as well as possible with chronic, debilitating, and life-threatening conditions.

Some years ago, I was hospitalized with viral meningitis on my return home from a consultation in Morocco. I was informed of the diagnosis but received no information about what I might expect. The first few nights, nurses woke me repeatedly but never told me why, so I presumed that it was to make sure I was still alive. After a week, I was informed that the crisis period was over, my EEG appeared normal, and I could go home and resume "normal activity." When I asked for guidelines, I was told only to "avoid stress for a while." My husband was told I might be "a little irritable." That weekend, I hosted a dinner party for visiting friends—for me, a "normal activity," celebratory and fun, and not what I considered stressful. I collapsed before the end of the evening. At my follow-up appointment with the neurologist, I was angry. I asked for clearer guidelines: "How should I know what's too stressful?" I'll never forget his reply: "If you walk to the corner and need an ambulance to get home, then that was too much." This was not helpful. If I only found out *after* I required an ambulance, I had no guidelines to protect myself and avert a health crisis.

The year that followed was a long nightmare as I struggled to meet the demands of a flourishing career and of parenting an active 3-year-old child. I could pull myself out of bed to get my daughter off to nursery school and then teach a 3-hour seminar, only to collapse with piercing headaches, dizziness, and exhaustion for the rest of the day. I had no memory of what I had said in class. I tried to work on a book draft, only to have excruciating difficulty finding words and forming coherent sentences. My doctor was amiable but patronizing, each time telling me simply to "take it easy" and I'd soon feel better, as if I were exaggerating my difficulties to gain sympathy. I felt helpless and despairing. My resilient self was not bouncing back.

After a year of "taking it easy," I was still not much better. I consulted another neurologist, whose further tests found that I had suffered neurological damage, especially to the vestibular system. Despite the bad news, this physician was more helpful and hopeful. His approach was closer to a healing and resilience philosophy than to the traditional treatment paradigm. Its core assumption: the human brain has considerable plasticity. It is able to repair itself and modify its wiring to compensate for injury and loss *if* we actively mobilize our resources for recovery. Working collaboratively, he took time to listen to my concerns and answer my questions, gave me informational brochures, drew diagrams of the brain injury, and helped me to comprehend my illness experience. Medication controlled the pain and dizziness. Convinced that the brain, like other parts of the body, needs exercise to function well ("use it or lose it"), this physician recommended a program of strengthening exercises to reduce my vulnerabilities and restore my mental energy and functioning. He encouraged me to persist in my teaching and writing efforts, but in an incremental way to regain my proficiency gradually. He helped me to not become discouraged when symptoms worsened at times of high stress, to anticipate such times in the future, and to restructure my life to buffer stress more effectively. Months later, much improved, I asked him how he and my first neurologist could have approached the same patient so differently. He laughed and said, "I've known Dr. X for years; we play tennis together. When he has an injury, he stops playing for months and takes it easy. When I have an injury, I get physical therapy and get back on the court as soon as I can. It's all in our world view."

Indeed it was. Yet I was also fortunate, as some serious conditions cannot be improved. Looking back, I can see that the successful approach to my case embodied many of the key processes in resilience and was based in a collaborative therapeutic partnership. Unfortunately, one link was missing: inclusion of the family. Although I came through the worst of the ordeal personally strengthened and able to care well for my child, my marriage, already strained, didn't survive. Yet the many months of quiet contemplation enabled me to gain a new perspective on my life. My friends were my mainstay. I learned to reduce my work overload, focus on the things that really mattered, set aside petty grievances, and find more joy in life. Over time, I had to come to grips with the long-term sequelae of the brain injury. I learned to compensate for losses: Left-handed, I lost strength and coordination in my left hand, so I had to build my right-handed abilities—and one-handed keyboard agility. I had to overcome impaired vision and dizziness. I chuckled at one specialist's remark: "Your eyes really don't work together, do they?" In mastering the ongoing challenges, I was grateful for the deeper wisdom and bonds forged by the experience. I learned to practice the art of the possible.

THE ILLNESS EXPERIENCE: A SYSTEMIC PERSPECTIVE

A family resilience approach to serious illness is grounded in a systemic orientation; it involves language and concepts that humanize the challenges of illness and encourage optimal functioning, personal well-being, and relational connection.

Biopsychosocial Orientation

An integrated biopsychosocial orientation to psychiatric and medical disorders is widely advocated but not readily put into practice. Emotional, interpersonal, situational, and environmental stresses all contribute to a wide range of symptoms, lower physiological immunity and neurological functioning, increase the risk, course, and severity of health problems, and can hasten death. Medical training and practice increasingly aim toward treating the whole person, yet integrated care is primarily symptom focused, and family and social influences receive insufficient attention (McDaniel, Doherty, & Hepworth, 2013; see also the website of the Collaborative Family Healthcare Association at *www.ccfh.net*).

It is well documented that physical illness significantly impacts family functioning and that family beliefs and practices can influence the physical and mental health of members (Campbell, 2003; Carr & Springer, 2010). When living with a serious condition—from diabetes, cancer, or multiple sclerosis, to traumatic brain or spinal cord injury, to major mental illness—individuals and their families need to cope with crises and navigate a challenging terrain over time.

Although most studies of family influences have focused on the negative, family systems approaches reveal the positive impact of family strengths on the course of illness and quality of life for all family members (Weihs, Fisher, & Baird, 2001; Rolland, 2012). Efforts to strengthen family resilience can buffer stress, bolster neurophysiological immune processes, and contribute to enhanced functioning and well-being. A family resilience framework connects individuals with their families, communities, and cultural and spiritual resources. This holistic approach increasingly integrates Eastern medicine and such teachings and practices as mindfulness meditation and yoga, along with Western models of care (Walsh, 2009c).

Addressing the Cultural and Spiritual Dimension of Illness, Suffering, and Resilience

Illness and suffering involve cultural and spiritual matters, opening questions about the human condition, our physical, mental, and emotional vulnerability, and our mortality (Wright, 2009; Wright & Bell, 2009). In a multicultural society, our clients' varying ethnic traditions, spiritual beliefs, and healing practices must be understood, respected, and integrated in practice (Falicov, 2009; Walsh, 2010). For instance, many ancient cultures have understood mental disturbances as forms of possession by spirits. Many immigrant families turn to indigenous healing approaches alongside Western medicine and may not mention their beliefs and practices if not asked. Kirmayer, Dandeneau, Marshall, Phillips, and Williamson (2011) found that the cultural and spiritual traditions of immigrants, refugees, and indigenous peoples in Canada are powerful sources of resilience in coping with serious health and mental health challenges. Their extensive research informs their call for an integrative orientation in all mental health services, particularly for oppressed and marginalized groups, to draw on resilience-enhancing family and tribal traditions and the power of connectedness with communities, the environment, and the spiritual realm beyond.

The Illness Experience in Families

The term *illness experience* best captures the essence of living with symptoms and suffering (Kleinman, 1988). It refers to how impaired persons and members of their family and social network perceive, cope with, and master the physical and psychosocial challenges associated with painful symptoms, disability, and treatments. Life-threatening or life-shortening conditions pose the challenge of carrying on with life in the face of an uncertain prognosis and anticipation of death and loss (Rolland, 2012). When illness strikes a loved one, the entire family requires attention for optimal coping and adaptation.

In practice, for instance, the therapeutic discussion of a woman's experience of breast cancer, mastectomy, and radiation and chemotherapy treatments would broaden to include how it affects her sense of identity, body image, and sexuality; her mental functioning ("chemo brain" symptoms); bonds with intimate partners and children; family and job responsibilities; and life priorities in the face of possible recurrence. With all medical conditions, we explore such questions as:

- How are family, work, and social functioning affected?
- What is the illness experience for the spouse? For children?
- How can a couple shelter their relationship to weather strains over time?
- How can parents approach their children's concerns about loss? About the threat of the same condition for themselves?
- How can helpful extended kin and social resources be mobilized?

With advances in genomic science and technology, clinicians increasingly will need to help individuals and their families grapple with decisions about genetic testing, sharing results with others, and informing children, siblings, or other family members who may be at risk for heritable disorders (Rolland & Williams, 2005). Yet genetic predisposition does not determine fate. Recent epigenetic research reveals the potential family and environmental influences in the expression and course of most genetic conditions (Spotts, 2012), underscoring the need to strengthen family processes.

As helping professionals, our approach to illness can facilitate coping and adaptation. Our images and language need to convey respect and humanize an illness experience, for example, referring to a "person with a disabling condition." Caution is needed to keep the diagnosis of a chronic disorder from reinforcing pessimistic views of limited lives or hopelessness. At the other extreme, unrealistic images of superstars who defeat all odds, while inspiring, can inflame feelings of failure for those unable to forestall or reverse a devastating condition. With medical advances, more people are living longer with chronic conditions that vary widely in their course, severity, and degree of functional impairment. Although they may not (yet) be curable, most can be managed well through individual and family efforts, with collaborative health care systems and community resources (Rolland, 1994, 2012).

The needs of "well" spouses, caregivers, siblings, or other family members also require attention. Those who are consumed by caregiving demands are at risk for depression, illness, and premature death. Yet, if not overloaded or lacking in support, most do well and many find their relationships enriched through meaningful involvement and mutual support of family members through the challenges.

Family Systems Approaches to Health Care

In comprehensive systems-based health care, the family is the central unit of care in the integrated treatment of health problems and the accompanying psychosocial challenges (Heru, 2013; Kazak, 2006; McDaniel et al., 2013; Rolland & Walsh, 2005). Family interventions with serious illness address the ongoing mutual interactions of biological vulnerability and environmental stresses and supports. Interventions aim to help clients cope with and master illness challenges, to reduce stress, and to strengthen individual and family functioning and positive adaptation. We engage families as indispensable partners in a team approach. Enhancing their potential for resilience increases both patient and family quality of life.

Meeting Varied Psychosocial Challenges over Time

The particular challenges of specific illnesses vary; yet there are many commonalities, depending on the psychosocial demands and the timing of an illness. The family systems–illness model developed by Rolland (1994, 2012) provides a useful framework for evaluation and resilience-oriented intervention. The model casts the illness in systemic terms according to its pattern of practical, emotional, and interpersonal demands over time. The progression of a chronic condition involves the intertwining of the illness phases with individual and family life cycle patterns (see Chapter 9). How we help families think about success or mastery will vary with their challenges, their resources, and their values. The model addresses three dimensions: (1) psychosocial types of illnesses; (2) phases in their course; and (3) core family system variables.

On the first dimension, illnesses are grouped by key biological similarities and differences that pose distinct psychosocial demands on the individual and family. Illness patterning can vary in terms of onset (acute vs. gradual), course (progressive, constant, relapsing, or episodic), outcome (fatal, shortened life span with possible sudden death, or no effect on longevity), incapacitation (none, mild, moderate, or severe), and the level of uncertainty about the trajectory. Each psychosocial type of condition poses a pattern of practical and emotional demands that can be addressed in relation to the style, strengths, and vulnerabilities of a family.

On a second dimension, the concept of time phases provides a way for clinicians to think longitudinally about chronic illness and disability as an ongoing process that families navigate with landmarks, transitions, and changing demands. Crisis, chronic, and terminal phases have salient psychosocial challenges, each requiring particular family strengths or changes. For instance, the crisis phase involves the initial period of socialization to chronic illness. Family developmental tasks include (1) creating a meaning for the disorder that preserves a sense of mastery, (2) grieving the loss of the pre-illness family identity, (3) undergoing short-term crisis reorganization, and (4) developing family flexibility in the face of uncertainty and possible threatened loss. Gradually, families need to come to accept the persistence or permanence of a chronic condition, learn to live well with illness-related symptoms and treatments, and forge ongoing collaboration with professionals and health care systems. In the chronic phase, families must also pace themselves to avoid burnout, rebalance relationship skews (e.g., caregiving), and juggle the competing needs and priorities of all family members. They need to find ways to conserve or revise individual and family goals, accounting for constraints of the illness, and to sustain intimacy in the face of threatened loss. With a life-threatening or fatal condition, families do best when they shift their views of mastery and control over the illness to making the most of precious time.

The psychosocial demands of a condition are addressed in relation to each phase of the disorder. The model informs an assessment of ways the illness interfaces with individual and family dynamics and development; the family's multigenerational history of coping with illness, loss, and other adversity; and the meaning of the illness experience for family members. Key processes in family resilience, involving belief systems, organizational patterns, and communication processes, can be targeted as they fit the evolving situation. The Rolland framework can guide periodic family consultations, or "psychosocial checkups," as salient issues surface or change over time. Family psychoeducational groups and support networks can provide useful illness-related information, management guidelines, and support for family members in meeting caregiving challenges, coping with the myriad of stresses, and making the most of their lives.

As therapists, we need to be flexible in helping families to meet emerging challenges over the uncertain course of a serious, life-threatening illness.

> I worked with Kate, a vivacious woman, periodically at various phases and transitions over 8 years of her journey with breast cancer. She and her husband, Wayne, showed remarkable courage and resilience through two recurrences, with active initiative in searching out the best treatment options and keeping informed of medical advances. I coached them to listen and respond sensitively to their children's concerns as they emerged, and to keep channels of communication open. Wayne was supportive of Kate and flexible in shifting his work schedule to be more available in parenting their three children during difficult periods. A few couple sessions were held at a time when Wayne became remote, to explore his unexpressed fears of loss and of inability to manage parenting responsibilities on his own. Kate decided to maintain her part-time clerical job, which she experienced as "an island of normality," taking her mind off her own condition as she tackled mountains of paperwork and enjoyed socializing and light banter with coworkers. She was open in informing colleagues of major changes in her status or treatments, and took time off when needed. Otherwise, she preferred not to discuss her illness at work, keeping a boundary to preserve non-illness-focused aspects of her life. She took "long vacations" from therapy during periods of remission and stable plateaus, wanting to "just smell the roses." Yet, she called proactively when new complications loomed on the horizon. Sometimes she came in when, as she put it, she lost her compass and needed to reorient herself on her journey.
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> A year ago, when the cancer spread to her lower spine, Kate underwent an experimental bone marrow transplant, once again beating the odds and doing well over the critical months. However, in the midst of her recovery, her 70-year-old mother was diagnosed with untreatable colon cancer, which progressed rapidly to death. A month later Kate called, concerned about Mollie, her 12-year-old daughter. She had found a letter that Mollie had written to a friend saying that she was desperately unhappy and wanted to run away. We held a family session, where at first Mollie railed against her teachers, wanting to go away to boarding school because "life sucks!" When I asked how the grandmother's recent death had affected family members, Mollie's eyes filled with tears. Her parents' receptiveness helped her to share her fear: "Grandma's death scared me so much. She had cancer, and Mom has had cancer three times. If *she* could die, so could Mom. Sometimes I have nightmares that the cancer hasn't all gone away. Then I just want to run away." Both parents held her, soothing her as she sobbed. Mollie's siblings were encouraged to share their feelings and concerns as well. I supported the parents' efforts to talk about the dilemmas in living with uncertainty and their wish that they could just make the cancer go away once and for all. Both parents reassured the children that Mom indeed was continuing to do well and vowed to be honest with them if the situation changed. The discussion turned to ways they could make the most of family time together.

This case illustrates how systemic therapists may combine individual, couple, and family sessions, holding a resilience-oriented systemic map to guide intervention priorities over time. Even when parents handle an illness experience as well as possible at one crisis point, others will arise later that require further conversations. Here, the death of the grandmother shattered the shared optimism (positive illusions) that the mother would always continue to beat the odds. Also, developmental transitions are nodal points when new concerns often surface. As Mollie approached adolescence, she had greater comprehension of her mother's condition and all it would mean to lose her. She also began to worry about her own risk of breast cancer. The time had come to talk more openly about those issues.

Coming to terms with an illness and its ramifications is never a once-and-for-all matter, but a process worked on periodically over time. Kate's long-term goal was to be there for her daughters until they were independent, which she first defined as getting their drivers' licenses. At that milestone, she set a new goal: until they were launched and off to college. When that transition occurred, she met with me, saying, "Well, I guess I'd better come up with a new reason to keep on thriving!" We talked about meaningful pursuits for her and travel she and her husband would enjoy together. Such life-cycle transitions can be valuable touch points for consultation.

Keeping the Illness in Its Place

With a serious and chronic condition, families can't simply "bounce back" to the old normal life, but must navigate a new terrain, which some describe as "leaving the normal world and entering the illness world." It is crucial for families to gain a perspective on the illness so it doesn't define individual identity or rule family life. The challenge is to recognize the influence of the condition, master what is possible, accept what is beyond control, and come to terms with living with it well. To do this successfully, families need to find ways to "put the illness in its place" (Gonzalez & Steinglass, 2002). Setting boundaries as to when, where, and with whom illness concerns are discussed can be helpful, just as Kate (above) kept boundaries in her work life to preserve what she called her "island of normality."

Over time a chronic condition can skew a couple relationship between the impaired partner and the caregiving or "well" spouse (Rolland, 1994). The persistent intrusion of an illness into all aspects of family life can fuel despair.

> Mike and Delores, a working-class couple in their mid-40s, came for therapy as growing conflict threatened the survival of their marriage. In the first session, they argued over money, sex, and Mike's whereabouts on weekend nights. Neither partner mentioned that Delores had been suffering for many years from multiple sclerosis, despite her evident difficulty in walking with a cane. When asked about her condition, both minimized it as "nothing new" and resumed fighting over petty grievances.
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> Separate individual sessions were held to hear more about the illness experience for both partners, affording each the opportunity to express concerns more freely. Mike revealed that he was alternately depressed and furious at Delores because of her increasing disability and dependence. They had traditional breadwinner–homemaker roles in their marriage. As her illness progressed, she was less able to keep the house clean or to manage cooking, shopping, and errands, and had lost all interest in sex. It bothered Mike to come home and find her "lying around" while he worked an exhausting construction job plus overtime to keep up with her medical bills. He harbored fantasies of leaving her, became irritated with her over small things, felt ashamed, and then drowned his frustration in bouts of heavy drinking at a neighborhood bar on weekends. As for Delores, the less she felt in control of her body, the more controlling of Mike she became. She alternated between feeling guilty for being such a burden on him and then irritated and resentful that he wasn't more attentive to her needs.
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> In the next couple session, it was important to reframe the relational distress as not attributable to his failings or hers, but rather as a shared dilemma arising from the burdens imposed on their lives by a progressively debilitating illness. Appreciation of the impact of the illness enabled the spouses to hear and comfort each other as they shared the ways each had been affected and how it had ravaged their relationship, their financial security, and their future hopes and dreams. Strains also concerned the uncertainty about the future progression of Delores's condition and the possibility of early death. Their marriage was strengthened as they pulled together to find ways of reducing the intrusion of the illness in their lives and to find pleasure together. Delores, reassured that Mike's night out with the boys was not an extramarital affair, encouraged him to go out to sports games he enjoyed when she couldn't; in turn, he agreed not to drink to excess. Feeling less trapped, he was kinder toward Delores and supported her need for outlets and visits with friends. Knowing her love of nature, on his days off he took her to nearby parks and the Botanic Garden to brighten her spirits. They decided to set aside a little money each week toward a trip for their upcoming anniversary.

When the cumulative effects of a chronic illness loom increasingly large—imposing heavy physical, emotional, relational, and financial burdens, and diminishing future hopes and dreams—it is crucial to help clients regain a view of each person and their relationship as defined by more than the illness. Similar to White's (White & Epston, 1990) technique of externalizing the problem, the illness is framed as an unwelcome intruder; by joining forces family members can regain control of their lives. Couple therapy can help each partner gain empathy for the other's position, address such issues as guilt and blame, and rebalance their relationship, enabling them to live and love as fully as possible.

Key Family Resilience Processes: Navigating the Challenges of Chronic Illness

Recent studies have identified an array of ways that key family processes can be helpful in chronic illness, particularly with childhood illness and physical, mental, and developmental disabilities (Beavers & Hampson, 2010; Greeff & Nolting, 2013; Greeff, Vansteenwegen, & Gillard, 2012; Greeff & van der Walt, 2010; Knestricht & Kuchey, 2009; Levine, 2009; McCubbin, Balling, Possin, Friedrich, & Byrne, 2002; Retzlaff, Hornig, Müller, Gitta, & Pietz, 2006; Shapiro, 2012).

Belief Systems

The belief systems of the affected person, the family, their cultural and spiritual traditions, and their health care providers intersect in the illness experience and in all healing transactions. We may need to work with distressing causal attributions of how and why health problems have occurred or persist, as well as beliefs about the role of helping professionals and the family in the treatment process. For instance, several studies above find that a shared sense of coherence and a larger family vision or sacred beliefs contribute to family resilience.

Epidemiological research points to the importance of hope in the face of uncertainty with life-threatening conditions. Taylor (1989) found that cancer patients were better able to rally when they held "positive illusions" in their potential to overcome a poor prognosis. Unlike denial, this involves a choice to maintain a strong focus on healing and well-being while clearly understanding the grim situation. It fuels active initiative and perseverance in steps (such as stress reduction, social support, healthy diet, and exercise) to maximize the likelihood of a positive outcome. Even when patients did not live longer than expected, their quality of life and relationships were significantly more satisfying and meaningful as they made the most of precious time.

In helping families initially face elevated risks of death and loss with a health condition, it is important not to undermine their hope and to encourage their best efforts for optimal well-being and quality of life. If an illness progresses, sensitivity is needed in helping families to reconstruct the meaning of realistic or reasonable hope (Weingarten, 2010) as they confront the greater *probability* of a poor outcome, such as a limited recovery or death. In the event of a terminal condition, and the *certainty* of death, they can be encouraged to redirect their hope, prayers, and efforts to the amelioration of pain and suffering, enhanced comfort, emotional and relational well-being, and spiritual peace of mind. Even then, the length of time they have to live may be uncertain, depending on such variables as the slow or rapid progression of a condition, as in amyotrophic lateral sclerosis (ALS). Feelings of hopelessness are common when a condition becomes incurable, suffering unbearable, or treatment overwhelming. In families, members may be divided between holding on to hope or giving up (Flaskas, 2007). Therapists need to allow space in the therapeutic conversation to discuss feelings of hopelessness, what hope means to various members, and, where possible, to support clients in reorienting to a new vision of hope and mastery of what is possible.

Making meaning of the condition and prognosis is crucial. It is useful to ask families what illness information they have received and what each member believes about the future course, exploring their best hopes and worst fears. When these beliefs are polarized among family members, it can generate strong conflict, particularly if decisions must be made about whether to pursue or forgo further treatment options. We can help families obtain clearer information about the medical prognosis, treatments, and management issues to guide collaborative decision making. As the course of a condition worsens, we can help families reevaluate their options and chances, and encourage their efforts to master the possible and accept what may be beyond their control. Although their best efforts may not result in the hoped-for outcome, they can greatly impact the quality of life and enhance their relationships. Activism and advocacy for prevention and treatment are a valuable pathway in resilience for families. One father, afflicted with multiple sclerosis, maintained a positive outlook despite a poor prognosis: “I'm not happy I have it, but I'm a happy man living with it.” Taking part in research gave his life greater meaning. “If I can help others it gives me satisfaction. My glass is half full—and I have hope for future generations.”

Organizational Processes

With severe disabilities, studies find that establishing rhythms in family life, such as consistent rules, rituals, and routines, fosters child and family resilience. Family organizational patterns may need to shift with various adaptational demands over the course of an illness. For instance, in a family with teenagers, a father's heart attack generates a crisis, drawing family members together in high cohesion. Family life is disrupted by the initial anxiety and turmoil. Over the following weeks, as the father recovers, the family restabilizes, regaining household order, resuming daily routines, such as shared mealtimes, and expanding attention to others' priorities, such as schoolwork and activities. Several months later, family functioning may remain closer and more structured. Members may be vigilant and cautious not to upset the father, out of fears of recurrence. An adolescent may be constrained from leaving home for college under pressure to support parents. Although all families change in response to a crisis, some need help in readjusting roles and interactional patterns to maximize their resources and coping skills, especially if a crisis recurs or a condition becomes chronic.

Communication

Positive patterns of communication facilitate family resilience in dealing with serious health challenges. Open communication in families and with health care providers is vital to clarify an illness diagnosis, prognosis, treatment options, and management guidelines. Framing events, such as receiving a diagnosis, cast meaning on a serious condition and may help or hinder in dealing with it (Rolland, 1994). Health care professionals may unwittingly contribute to blocked communication and isolation among family members by telling only a spouse or parent about a life-threatening prognosis. Some might presume that it is unwise to talk openly about it together or harmful with the patient. When clinicians sensitively help family members to share information and clarify an illness situation and options, they are better able to support each other in mastering their challenges.

Clinicians also need to explore cultural differences and each family's preferences. In traditional Japanese culture, the family may be told that their loved one is dying but the patient is not told, for fear that it could hasten death. Yet we should not assume that all families would want to follow their traditional norm. Often, patients are aware of their condition but don't talk with loved ones about it, wishing to spare them upset. Care needs to be taken not to contribute to a "conspiracy of silence," which can rob them of opportunities for important conversations.

Studies have shown the importance of good communication in the adaptation and competence of families with a child with serious physical and mental disabilities. Countering assumptions that families inevitably suffer chronic sorrow and dysfunction, those families who dealt openly with their feelings adapted well, increasing their mutual support with members able to express a wide range of feelings, including joy. As one critically ill young girl said: "We have to live and love it up!"

Collaborative Caregiving Team

A family resilience approach expands our society's narrow, individualistic focus on a designated primary caregiver to involve all family members as a caregiving team. Family intervention priorities include (1) stress reduction; (2) information about the impaired member's medical condition, functional abilities, limitations, and prognosis; (3) concrete guidelines for sustaining care, problem solving, and optimal functioning; (4) linkages to supplementary services to support family efforts; and (5) focus on ways for family and friends to share meaningful and enjoyable contact. To meet caregiving challenges, communities must support families through a range of services from day programs to assisted and communal living and commitment to full participation of individuals with disabilities in community life.

Illness and Caregiving in Later Life

With the aging of societies and medical advances, more elders are living longer with chronic health conditions (Qualls & Zarit, 2009). In the United States, health problems and their severity vary greatly with disparities associated with income, race, and adequate, affordable health care. While more people are healthy through their 60s than in the past, for those over 75—and especially for frail elders over 85—progressive, degenerative physical and mental conditions and chronic pain are increasingly common and require long-term care.

Family caregiving for elders can be demanding and strain intergenerational relations. Issues of autonomy and shame-laden dependence also come to the fore as aging parents lose functioning and control over their bodies and their lives (see Chapter 9). As family size decreases and childbearing occurs later, those at midlife—the so-called "sandwich generation"—face multiple pressures: meeting job demands, raising children, and caring for aging parents, grandparents, and other relatives. Caregiving has burdened women disproportionately in their roles as daughters and daughters-in-law. In our mobile society, adult children often live at a distance; shuttling back and forth further strains the ability to provide support in times of need. Adult children past retirement age, facing their own declining health and resources, increasingly assume responsibilities for infirm parents in their 80s and 90s.

Family and friends are the front lines of support. Growing numbers of elders with chronic conditions receive home-based care for daily functioning and require costly medications and periodic hospitalizations. Prolonged caregiving can take a heavy toll in depression, anxiety, and health decline. Some aspects of elders' chronic conditions are especially disruptive for families, such as sleep disturbance, incontinence, delusional ideas, and aggressive behavior. Useful management guidelines, support groups, home health aides, and day care programs can reduce exhaustion and revive spirits.

Progressive Dementias: The "Long Good-bye"

Progressive dementias, affecting over 40% of elders over 85, are especially challenging for families (see also Chapter 9). Alzheimer's disease, accounting for most dementias, is one of the most devastating illnesses of our times. Dementia gradually strips away mental and physical capacities, with gradual memory loss, disorientation, impaired judgment, and loss of control over bodily functions. The irreversible disease course, called "the long good-bye," can persist for 10 to 20 years. Families need help in dealing with the many ambiguous losses (Boss, 1999), including gradual loss of identity, family roles, relationships, and even recognition of loved ones, who are confused with others, even those long deceased. Finding humor can lighten spirits.

> Danny, who was devoted to his parents, found his father's worsening dementia heartbreaking and lamented the frustration and sadness it caused his mother, who tended to him despite her own medical ailments. Danny had dinner with them frequently to help out. One night, as his mother cleared the table, his father leaned over to him and said, "See that woman over there—she's a darn good cook and good-looking, too. If I wasn't a married man, I could really go for her!" Danny hugged his father and replied, "Pop, you're a lucky man—because you ARE married to her! She's your wife!" They all had a good laugh, his mother was pleased by the compliment, and they retold the story many times.

Bonds with companion animals are found to facilitate resilience for elders with declining health (Walsh, 2009a, 2009b). One grandfather with dementia could no longer follow family conversations but found contentment petting the family dog, snuggled close to him on the sofa. He took great delight in sneaking sausages under the dinner table to his attentive companion. Service dogs, trained to assist persons who are functionally impaired or have life-threatening conditions such as diabetes or seizures, provide vital companionship and enable them to live independently.

We would be mistaken to view later life only as a time of decline and loss. This period also holds potential for personal and relational change and growth (Walsh, 2012b). One father's cognitive decline was accompanied by a softening of his prickly defenses and mellowing of his affect from his former gruff demeanor, enabling his adult children to engage more warmly with him. The challenges of caregiving also present opportunities for greater intimacy and for healing relationship wounds.

Difficult Family Dynamics

Intergenerational tensions often arise over dependency issues (Walsh, 2016b). It's helpful for family members to appreciate that meeting increasing parental needs is a normative filial responsibility, not a parent–child "role reversal." An aged parent deserves respect as a family elder, with declines in functioning not demeaned as "childlike." Family therapists can open conversations about dependency issues with sensitivity and a realistic appraisal of strengths and limitations. An elderly father driving with serious impairment may be unwilling to admit dangers or give up his autonomy. Adult children can be encouraged to intervene respectfully while supporting their elders' desire to be as fully engaged in life as possible.

When past grievances have ruptured family relationships, caregiving and life-and-death decisions often become more complicated. If one adult child steps in and becomes overburdened, resentment can brew toward others on the sidelines. Yet a medical crisis can become an opportunity for family members to heal strained relationships and collaborate as a caregiving team.

> Joellen, a 38-year-old single parent, came to therapy with an agonizing dilemma. Her father, hospitalized for complications of chronic alcohol abuse, had asked her to donate a kidney to save his life. She felt enraged to be asked to give up something so important when he had not been there for her as a father. He had been a mean drunk, often absent and many times violent. She was also angry that he had brought on his deteriorating condition by drinking and had refused to heed his family's repeated pleas to stop. Yet, as a dutiful daughter and a compassionate woman, she also felt a sense of obligation and guilt: She did not want her father to die because she had denied him her kidney.
>
> I broadened the dilemma to include Joellen's siblings, suggesting that she discuss it with them. But she dismissed that idea, saying that they had been estranged for many years and were rarely in contact. So I encouraged Joellen to talk with her mother—who informed her that her father had also asked her siblings for the kidney donation. She was furious that old rivalries were stirred up as to who would be seen as the good, caring child or the bad, selfish ones. Fired up, she now took the initiative to get her siblings together. When the meeting proved hard to schedule, I encouraged her to keep trying. When they met, old rivalries melted as they began to grapple with the shared dilemma.
>
> I refocused the discussion with questions about the future, wondering if they had considered that other challenges would likely arise in caring for both aging parents, or the surviving parent, if widowed. They had avoided looking ahead, but I encouraged them to begin thinking about ways to collaborate as a team in meeting future challenges—and the immediate crisis. With this conversation, the oldest brother, Vick, volunteered to donate his kidney for their father. He said he felt less conflicted remembering good times with him in earlier years before the problem drinking. The others then stepped up, agreeing to support him through the surgery. As the beginning of a new solidarity was forged, all agreed to keep in contact and come together around their parents' future needs. Over time, Vick shared stories of their father's life struggles, expanding his younger siblings' understanding and compassion for him.

Family members commonly distance out of sheer exhaustion and depleted resources. Recurrent crises can fuel helplessness, hopelessness, frustration, and escalating conflict. Some distance from painful past experiences, failed rescue attempts, anger over destructive behavior, or the fear that they will be pulled into a bottomless pit of selfless caregiving and the sacrifices extracted by an illness. Loss issues and survival guilt are common as well: "How can I be successful and enjoy life when my loved one's life has been devastated by illness?" Yet the relief of a cutoff is sometimes overshadowed by worry about the parents' well-being and later sorrow or guilt at abandoning them in their time of need.

My experience has taught me never to give up on relational recovery even—and especially—when physical recovery is not possible. My work with many in this position—parents, siblings, and adult children of frail elders—has heightened my appreciation of their many struggles and has strengthened my conviction that it is rarely too late to repair frayed bonds (see Chapter 14).

Placement Decisions

When declining health requires consideration of extended-care placement, it can be a crisis for the whole family. Placement is usually turned to only as a last resort—when family resources are stretched to the limit and in later stages of mental or physical deterioration or high risk of harm to oneself or others. Yet feelings of guilt and notions about institutionalization can make a placement decision highly stressful for families, especially when it is seen as abandonment in their family or cultural context.

> Mrs. Gupta called for help with her teenage son, stating that she "felt helpless to control" him and feared that he "needed to be institutionalized." A family assessment revealed an escalating cycle—his defiance of her attempts to control his every activity—over the past several months—since Mrs. Gupta's mother had been brought to live in their home. She wept as she described her mother's deteriorating Parkinson's condition, feeling unable to provide round-the-clock care. She couldn't sleep at night after finding her mother on the floor. Control struggles with her son deflected her heightened concern: that her mother's condition was beyond her control but "institutionalizing" her was out of the question. At her father's deathbed, a year earlier, he had asked her to promise that she would always care for her mother. She had also heard stories that in regions of India widowed women were banished from their homes and communities. She could not bear to abandon her mother. She felt alone with her dilemma, as her husband had distanced, preoccupied by his work. In a couples session, he acknowledged that he was avoiding his own guilt over having left the care of his dying mother to his sisters. The family crisis now became an opportunity for him to support his wife and mother-in-law's well-being. The couple's bond was strengthened as they explored together how to provide the best care, with in-home nursing assistance or in a nearby care facility, without abandoning their loved one—or each other.

Family sessions can help members to assess needs and resources, weigh the options of in-home and placement options, and share feelings and concerns before reaching a decision. Often through discussion new solutions emerge that can support the elder's remaining in the community without undue burden. Home-based health care services and community backup resources are vital for the respite and well-being of family caregivers. When placement is needed, we can help families see it as the most viable way to provide good care and help them navigate the maze of options.

Terminal Illness

Families face many painful challenges with terminal illness. Dilemmas may include whether and how long to pursue more treatments with little or no chance of prolonging life, toxic side effects, and lowered quality of life for the remaining time. When the dying process has been prolonged, family caregiving and financial resources depleted, and the needs of other members long on hold, relief at ending the strain on the family can be guilt-laden for survivors. Clinicians need to attend to unmet needs for pain control and palliative care, and to worries about financial and emotional burdens on loved ones. Family collaboration is essential to reduce suffering and make the best arrangements to keep the seriously ill person comfortable and comforted while balancing the needs of other family members.

Families need wise counsel as they approach life's end and grapple with personal, cultural, and spiritual matters (Walsh, 2009d). Gawande (2014) encourages health care professionals to have vital conversations with patients and their loved ones, exploring four basic questions: What is their understanding of their health or condition? What are their goals if their health worsens? What are their fears? What are the trade-offs they are willing to make and not willing to make? Most important are conversations about their priorities as they approach death and loss. Some prioritize living long enough for a project completion or a special event, such as a child's graduation; others might prefer to end pain and suffering and forgo further treatments.

Advanced planning of end-of-life wishes is advised. Clinicians can help family members discuss living wills, share feelings about complicated situations, weigh various options, and come to terms with decisions taken. Over time, such decisions should be reviewed and flexibly revised to fit changes in health status, as people's priorities commonly shift over the course of a disabling condition. In some cultures it is taboo to plan for death or discuss it openly, so clinicians must be sensitive to family beliefs. Increasingly, families face agonizing end-of-life dilemmas. There is growing public support in the United States for physician-assisted dying when requested by someone who is terminally ill to enhance dignity, peace of mind, and control over the dying process. Decisions to maintain or withhold life support efforts for a loved one raise fundamental questions of when life ends and who should determine that end, involving medical ethics, religious beliefs, patient/family rights, and even the possibility of criminal prosecution. Families can be torn apart by opposing views and decisions.

A terminal illness may hold unexpected gifts, particularly at life's end, when family members fully engage with loved ones and make the most of precious time.

> James, age 52, came to talk with me about his unbearable sorrow at his mother's terminal illness. We explored his complex feelings. A devout Catholic, she had done all she could to keep her family intact while enduring an abusive marriage and many relocations that uprooted the family due to his father's alcoholism and repeated job loss. After the father's recent death, James had bought a new home for his mother in high hopes that, at last, she could enjoy her later years in peace and comfort. He was devastated that her illness so quickly shattered these dreams. "It's just not fair! She deserved some good years."
>
> He and his sisters had scattered around the country in adulthood and maintained little contact. Since their mother's cancer diagnosis, she had uncharacteristically asked them to make several trips to visit her. Now she had just called them together, he feared, for their last good-byes. He was tormented as he left for the visit.
>
> When I saw him after his return, he seemed transformed: his inner turmoil had subsided, although his mother, indeed, had died during the visit. He told me, "I knew my mother was a strong woman, but she was most amazing as she faced her own death—she deliberately brought me and my sisters in to care for her, time and again, to knit us back together. Her final request made sure that we'll continue our bonds. She told us she didn't want to be buried where she lived, so far from her children and her roots. Instead, she asked to be cremated and that we take the urn with her ashes and travel together to each town where our family had lived and scatter some of her ashes in a beautiful place we had enjoyed. Her courage inspired us to go even further in honoring her wishes. We told her we would save a portion of the ashes and make a trip to Ireland together to scatter the last remains in the town of her grandparents, which she had always wanted to visit. She was so pleased and died peacefully a few hours later as we sat around her singing Irish ballads she had loved.

This potential for transformation, forged in the midst of suffering, dying, and loss, distinguishes the concept of resilience from coping well. As we've seen, resilience entails more than shouldering a caregiving burden, bearing the sadness of loss, or adjusting dreams downward. This moving story reveals the core of relational resilience: Family members rallied together to practice the art of the possible. They made the most of limited time together and transcended the immediate death and loss, inspired by their mother to carry out her wishes, thereby honoring and sustaining her memory and spirit. In the process, they and their bonds were transformed. In resilience-oriented practice, we can facilitate such processes.

FAMILIES COPING WITH MENTAL ILLNESS

We now have ample evidence of the complicated mutual influences between biogenetic vulnerability and family and social environmental factors in the expression and course of major mental disorders (e.g., Tienari et al., 2004). Yet, a biopsychosocial orientation is not well integrated into most treatment, currently prioritizing psychopharmacological and cognitive-behavioral approaches. I was fortunate that my first year of clinical training in 1968 was on a model psychiatric inpatient unit (T-1) at Yale Medical Center, combining individual, group, family, and multifamily therapy approaches with newly developed psychotropic medications. My very first family therapy experience taught me the value of this multilevel approach:

> Emmy Lou was admitted to the psychiatric unit during an intense psychotic episode. She had been suffering from bipolar disorder for over 20 years. Walt, her devoted husband, took her to the best treatment centers; stood by her through recurrent breakdowns, hospitalizations, and brief recoveries; and never stopped hoping for an effective treatment.
>
> As Emmy Lou began taking lithium, a newly experimental drug at that time, she and her family were also referred for family therapy. A first-year psychiatry resident and I eagerly worked with our first family, and as Emmy Lou made an astounding recovery, we jokingly credited our skillful family interventions.

Even when a condition is biologically based and responds to psychotropic drugs, family involvement in treatment is crucial for optimal patient and family adaptation. The family didn't *cause* her disorder, but they too suffered its impact. The family members didn't *need* Emmy Lou to be ill; nor did her symptoms serve a function for them (mistaken beliefs by some early family therapists). However, they had structured their family life around her dysfunction over the years. Any recovery, while everyone's greatest wish, involves a disruptive transition. Although medication can reduce florid symptoms, loved ones must reorient their relationships and patterns of living. And, as with a serious condition and drug treatments, the path forward may not be smooth.

> It was important to help Walt and their two teenage sons relate to Emmy Lou not as a chronic patient, but as a beloved wife and mother recovering from a devastating condition. To enhance her functioning and worth, they needed to alter patterns of family functioning set in place over the years to compensate for her deficits and diminished

> sense of self. Walt had increasingly taken over parenting and household responsibilities, with Emmy Lou assigned to menial tasks such as walking the dog. To restore her competence and confidence, the parental partnership needed to be rebalanced. Walt and their sons needed to shift their expectations. They were nervous and uncertain about how to relate without the illness defining their roles and relationships.
>
> Discharge planning and posthospitalization reentry sessions—critical components of the treatment unit—enabled Mary Lou and her family members to share their hopes and concerns and to reorganize family life. We scheduled a follow-up family session for early spring, the time they anticipated a recurrence. This offered an opportunity to discuss fears of a setback, to adjust medication, and to sustain the family's gains.

To optimize functioning and reduce the risk of serious relapse, it is crucial to engage family members as partners from a hospital admission through discharge, with planned follow-up and referral for outpatient sustaining care. The first few weeks and months postdischarge can be the most challenging. Relational tensions commonly mount as difficulties arise. It is helpful to support realistic expectations and offer useful guideline, reorganizing stressful interactional patterns and building communication skills to strengthen both individual and family resilience.

From Deficit-Based to Resource-Based Therapeutic Approaches

A focus on deficits, reinforced by psychiatric nomenclature, exerts a powerful influence in clinical practice. When those with recurrent emotional distress seek help, they often carry pathology-loaded baggage from previous treatment experience. A resilience-based approach aims to transform this experience.

> Jessie and Ted, a recently married couple in their late 20s, sought help for Jessie's phobic anxiety, which prevented her from leaving their apartment without a panic attack. She was evaluated for psychotropic medication, which lowered the intensity of her anxiety; yet she remained alone in the apartment all day, becoming increasingly depressed and ruminating about the emptiness of her life and the hopelessness of her emotional problems. The couple had recently moved from Jessie's hometown for Ted's new job. In the first few sessions, Jessie talked at great length about her "dysfunctional family," her mother's chronic drinking and depression, and her own recurrent episodes of panic, which had led to three brief psychiatric hospitalizations. She had spent the last 6 years in psychoanalysis, with sessions several times a week until their move to Chicago. Now fearing she was coming "unglued" again, she was making crisis calls to her former therapist. Ted was attentive and caring toward Jessie, yet frightened by her agitated state and catastrophic fears.

A deficit-oriented therapy might have continued to focus on past family damage and Jessie's resulting limitations and emotional fragility. Some therapists might have felt sympathy for the "normal" spouse stuck with a "damaged" partner. Or they might have assumed both partners in a marriage to be equally dysfunctional, and searched for underlying pathology in Ted as well. A family resilience approach identified and encouraged their strengths and potential. Ted was solid, stable, and caring. His attraction to Jessie was understandable: she was a lovely woman, warm, affectionate, attractive, and smart. Ted's fears from a past failed marriage also played a part. Recently divorced by a woman who had left him to pursue her career, he was reassured by Jessie's dependency and devoted loyalty. However, he neither anticipated her intense suffering nor "needed" her helplessness.

> As our sessions became dominated by Jessie's accounts of how her "messed up" family and her long history of emotional problems "explained" her current plight, I shifted focus to the recent transitional crisis in the couple's life—the disruption wrought by their relocation. I asked how the decision had come about. The partners had shared their feelings, concluded that on balance it would be a good move, and arrived at the decision jointly. Still, there was a skew in the experience of the transition, generating more stress for the more vulnerable partner. The move furthered Ted's career advancement and gave him a sense of pride. It also brought welcome contact with his family, who lived nearby. Jessie, who wanted to assume a homemaker role and hoped to start a family soon, had lost her community network, a satisfying job, and her therapist. She felt isolated in long, empty days in their apartment in an unfamiliar city. The loss of structure and support fueled her anxiety, rumination, and self-doubts.
>
> Helping the couple to make meaning of the recent symptoms in the context of this major transition was pivotal to Jessie's adaptation and the couple's resilience. I expressed my conviction that a major relocation is very stressful for a relationship as well as for individuals, and that by strengthening their resilience as a couple, they would both more likely make the best adjustment. To help them begin forming a new support network and to anchor them in their new community, I explored their interest in joining a church that fit their beliefs and lifestyle, encouraging them to make several visits. Within weeks they found a new "spiritual home" and a congregation of "kindred souls." Jessie met several women through the church who took her under their wing, helped her get oriented, recommended good neighborhood

resources, and accompanied her on errands. These small concrete supports eased her insecurities and helped her gain a sense of mastery over the "foreign" environment. As her comfort increased, we talked about the library job she had left behind and her love and knowledge of books. Ted encouraged her to volunteer in the church's fund-raising book sale. Her success in that endeavor led to a volunteer position with the neighborhood library. In turn, that experience led within a few months to a part-time job in a bookstore, a short bus ride away. With Ted's confidence in her, she overcame her "fear of becoming panicky" and excelled in the job, which she found to be a rewarding challenge.

It was vital to our work that Jessie stop defining herself as damaged, but rather broaden her identity as a likable and interesting person, with many assets as well as vulnerabilities. It was also crucial that she experience therapy not as a place to nurse old wounds endlessly (as in her past therapy), but as a place to develop latent talents and abilities. Jessie came to look back on her prior therapy as an addiction. Over the years, her vulnerability and overdependence on her therapist had increased to the point where she doubted her ability to survive on her own.

Our therapy ended successfully after 5 months. Jessie's medication was tapered off gradually. A year later, I received a birth announcement with a very cute baby picture and a note of appreciation for helping the couple launch their new life. Yet life doesn't follow an orderly course. Six months later Jessie called in a panic: Ted's company had been bought out, and he might be downsized out of a job. Over several sessions, the couple proactively considered possible options if a "worst-case scenario" required another move. When the ax fell a few months later, the couple was prepared and Jessie didn't panic. Ted had already begun a job search, landing a good position in a desirable community where Jessie planned to return to college. We met for a few sessions before the move, and I linked them to a trusted colleague there if the need arose. Jessie's physician recommended that she resume her antianxiety medication if needed during the expectable turmoil of the move. We scheduled a follow-up phone contact, and they sent a card at holiday time expressing their pride at how smoothly the new transition had gone. With all they had learned from their previous move, they now considered themselves experts on relocation. Jessie even thought about writing an article for a magazine on the subject.

Respectful Collaboration

Clinicians and investigators have long sought to understand and effectively treat the most debilitating mental disorders but have too readily

pathologized families. For decades, the concept of the "schizophrenogenic mother" blamed the purported character and parenting deficiencies of mothers for causing schizophrenia; "refrigerator mothers" were thought to cause autism. The family systems paradigm countered linear, deterministic assumptions to recognize the multiple, ongoing recursive transactions in the family unit. Still, some early family therapists focused on dysfunctional family processes in so-called "schizophrenic families" that were thought to maintain symptoms, approaching families adversarially as dangerous "barracudas" and calling their interactions "dirty games" (Anderson, 1986). However, strengths-oriented family therapists eschewed such pejorative approaches and emerging research confirmed a biological base in schizophrenia and found a wide range of functioning in patients' families (Walsh & Anderson, 1988).

Studies have examined the role of family processes in the future *course* of mental illness. For instance, high "expressed emotion" (i.e., critical comments and emotional overinvolvement) predicted later symptom relapse for highly vulnerable individuals. In studies of adopted-away identical twins with high genetic risk for schizophrenia, those growing up in families with communication deviance were significantly more likely to develop the disorder (Tienari et al., 2004). Notably, those studies also documented the importance of family protective factors: adoptive families with healthy communication patterns protected children at high risk from developing the disorder. By identifying such process elements, we can target interventions to lower stressful interaction patterns and enhance communication to strengthen both individual and family functioning.

Family Intervention and Psychoeducational Approaches

Research and practice developments have informed helpful family interventions with a range of serious and persistent mental disorders and developmental disabilities. Success depends on mobilizing family and community resources through collaborative relationships. Assessment and intervention engage family members as caring and vital resources for an impaired loved one's long-term adaptation. Interventions aim to reduce stress and strengthen a supportive network.

Clinicians need to counter the stigmatizing experiences of families who have felt blamed and shamed for their loved one's symptoms or failed treatment efforts. The family may be coping as well as can be reasonably expected in the face of recurrent psychotic or destructive episodes. Referral for family therapy should be disengaged from causal assumptions and based on the value of family involvement in strengthening effective coping and mastery with the stressful challenges of living with a persistent mental health condition.

Brief family therapy, providing structured, focused interventions, can be useful for strengthening individual and family functioning and reducing stress and conflict. It is crucial to set concrete, realistic objectives that can be tracked and tweaked, achieving small successes and a more solid base. On reaching a higher level of functioning and stabilization, gains can be sustained and setbacks averted with periodic family consultations or in multifamily groups.

Family psychoeducational approaches provide useful information, management guidelines, and social support. Combined treatment strategies that include family psychoeducation have been most effective in treating schizophrenia, bipolar disorder, major depression, and other serious disorders (Anderson, Reiss, & Hogarty, 1986; Lucksted, McFarlane, Downing, Dixon, & Adams, 2012; Miklowitz, 2010). Numerous studies have demonstrated the effectiveness of this approach in preventing relapse, improving recovery, and increasing family well-being. Drug maintenance may be needed to control the severity of symptoms and to prevent destructive behavior or repeated hospitalizations. Additionally, involvement in a social skills group and productive activity boost functioning and decrease isolation.

In the Anderson et al. (1986) model, a connecting phase established an empathic alliance, with the therapist attending noncritically to family needs and experiences and specific areas of stress in their lives. A daylong survival skills workshop providing information and management guidelines is followed by brief family therapy to support taking concrete steps toward stable functioning in the community. Monthly multifamily groups sustain gains. The basic principles of psychoeducation have been adapted for brief focused family consultation and effective prevention and early intervention programs (McFarlane, 2002). Family consumer groups critical of more traditional treatment have responded positively to these developments.

Psychoeducational multifamily groups are valuable with both mental and physical conditions (Gonzalez & Steinglass, 2002; McFarlane, 2002; Steinglass, 1998). They prevent or delay relapse, increase medication and treatment compliance, reduce stress, and improve individual and family functioning. Professionally led groups, typically with four or more families or couples, focus on ways to manage situational stress, loss, and transition while strengthening relationships and problem-solving abilities. The group context provides a social support network and opportunities for family members to learn from one another's experiences, to gain perspective on their own situation, and to reduce isolation and stigma, as well as guilt and blame. Group interventions may have a short-term or modular structure, typically as a daylong workshop, or 4–6 weekly sessions. Monthly meetings sustain gains, avert crises and setbacks, and address ongoing challenges and new or recurrent strains. Multifamily self-help groups are also useful in sustaining care and support over the long haul of a chronic condition.

Other family-based approaches have been developed in situations of maternal depression. Riley, Valdez, and colleagues designed Keeping Families Strong, using a multifamily group format to promote child and family resilience (Riley et al., 2008). Fortalezas Familiares (Family Strengths) is a 12-week community-based prevention program designed to address relational family processes and promote well-being in immigrant Latino families when a mother has depression (Valdez, Abegglen, & Hauser, 2012; Valdez, Padilla, Moore, & Magana, 2013).

Mobilizing Community Connections

Despite vital service needs, social policies and funding cuts have drastically reduced hospital stays, limiting them to treatment with medication and rapid stabilization, with inadequate outpatient services and community supports to sustain independent living. We see the failure of these policies in the tragic numbers of seriously troubled persons locked up in prisons or living precariously in the streets and shelters. The expectation for families to assume the primary caregiving burden over the chronic course of a mental illness, often with combined substance use issues, and the unresponsiveness to their concerns have led families to mobilize (Lefley, 2009). Consumer advocacy groups such as the National Alliance on Mental Illness (NAMI) provide valuable networks and information for families and lobby for more research and support. The Balanced Mind Parent Network (recently merged with the Depression and Bipolar Support Alliance) evolved out of efforts by families struggling with their youths' serious and volatile mood disturbances. Forming a virtual kitchen table community—a network of allies accessible anywhere, anytime—their web-based connections and programs share understanding and resources for educating, empowering, and ending isolation (*www.thebalancedmind.org*). As one mother said, "It's a beacon in our storm."

HELPING FAMILIES LIVE WELL WITH CHRONIC CONDITIONS

General Clinical Priorities

With serious physical and mental conditions, it is vital to build family strengths, resources, and successful coping strategies. Families are better able to handle stresses and to be more proactive to prevent and ameliorate future crises when we (1) identify and address common illness and treatment challenges; and (2) offer problem-solving assistance through predictably stressful periods. Flexibility is needed to tailor interventions and respond to family members as needs arise over the course of the illness and with changing life challenges. Priorities include the following:

1. Reduce the stressful impact of the illness/disability experience on the family.
2. Share information about:
   - The illness/disability, treatment approaches, and expectable course
   - Individual vulnerabilities, abilities, and potential
   - Importance of compliance with medication, treatment, or diet regimens, and physical therapy/rehabilitation to reduce vulnerability and enhance functioning
   - Expectable psychosocial challenges for the individual and family over time
   - Interaction with individual and family life cycle priorities
3. Offer practical guidelines through various phases of a chronic condition for:
   - Ongoing stress reduction
   - Managing symptoms, treatments, and complications
   - Problem solving and crisis prevention
   - Building strengths for optimal functioning and well-being
   - Respite and attention to other family members and life priorities
4. Provide links to services that support functioning in the community and the family's caregiving efforts, for example:
   - Home health care support
   - Day care, structured work programs, and social contact
   - Assisted living and group homes
   - National and local consumer groups; useful Internet resources
   - Faith-based communities and services

Family members facing the demands of a serious illness are often unsure whether they are doing too much or too little and how to navigate unfamiliar and challenging situations. They value information, management guidelines, and help in setting realistic expectations. A neglected family issue is the need for respite—time and space from illness and caregiving concerns for family members to meet their own needs, enjoy pleasurable shared experiences, replenish their energies, and revitalize their spirits.

Attention is also needed to the many losses that often accompany a chronic condition—loss of functioning or cognitive capacity, loss of limbs or disfigurement, loss of a sense of intactness and "normality," loss of valued roles and functions in the family, loss of employment and status, and loss of personal and shared hopes and dreams for the future.

> Mick, a construction worker left permanently disabled and wheelchair bound by the collapse of a building, began to drink heavily. One night Peg, his wife, found him passed out on the floor with his hunting gun ready to be fired. In individual and conjoint sessions, we explored the multiple losses he had experienced: his family role as breadwinner, his "tough guy" image, and the active life he had prized. In family sessions, he realized how much he was loved, valued, and needed by his wife and children, which was most crucial to his inner healing and resilience. Their support and encouragement recharged his will to go on living and make the most of his life, seeking new ways to be productive and active. As Peg increased her job from part-time to full-time, he took over cooking and helping with his children's homework, which provided new satisfactions and closer family bonds. Over time, he set up a web-based small business and began coaching his daughter's soccer team. He told Peg that although he never would have wished for his disability, his life and loved ones now meant more to him than ever before.

Crisis Intervention/Crisis Prevention

Crisis intervention is urgently needed by families in times of acute distress, since most chronic disorders involve periodic exacerbation of symptoms. Without such help, many individuals and their families veer from one crisis to the next, achieve few gains over time, and risk emotional exhaustion, serious conflict, and relationship cutoff. Therapists must be active and provide enough structure to help temporarily overwhelmed families reorganize and gain control of threatening situations. Because individuals with cognitive impairment may lack motivation, use poor judgment, or not take needed medication, family collaboration is crucial to sustain involvement in treatment and to reduce stress. Periodic "psychosocial checkups" and prevention-oriented consultations can be timed around major changes in a condition or disruptive life transitions to help families "bounce forward" with resilience.

Community-Oriented Family-Centered Health Care

Both family and community resilience can be nurtured if all helping professionals reach out to persons with disabling conditions and their families, respect their dignity, and work to forge viable extended kin and social supports. In many cases, basic needs for human connection and productive functioning can be met through such programs as structured group living arrangements and sheltered workshops, tailored to the vulnerabilities and potential strengths of residents. Families are essential resources in treating serious and persistent illness and disability. We can encourage collaboration, understand their challenges, and support their best efforts. Yet families cannot carry the burden alone. Despite rhetoric supporting strong families, family-centered prevention and intervention services are lacking, despite evidence of their effectiveness. Families and helping professionals must complete burdensome paperwork and navigate confusing and frustrating compliance and reimbursement bureaucracies. Families living in impoverished conditions, especially ethnic and racial minorities, are most vulnerable to the risks of serious illness and disabilities, caregiver strains, and inadequate health care and mental health services. A system of care—a spectrum of integrated family-focused services, medical, personal, social, and rehabilitative—is required. A continuum of care and community services is essential to meet changing needs over time and to sustain independent living, optimal functioning, and well-being.

Seeing Differences as More Than Disabilities

A resilience orientation embraces the whole person, supporting families' loving abilities to see beyond disabilities to cherish their loved one and encourage positive interests, abilities, talents, and potential. Moreover, many parents raising a child with autism or other developmental disabilities are quite resilient (Bayat, 2007) and view the family experience as a gain, not a loss (Dura-Vila, Dein, & Hodes, 2010). This is especially important in countering the stigma of mental disorders. Many individuals with difficult lifelong challenges forge satisfying and productive lives and find meaningful expression in music, the arts, and other arenas. Some have special gifts that can be nurtured by families. Temple Grandin, a remarkable woman with autism, credits her mother's love and dedication with helping her make the most of her life. She achieved an advanced academic degree and channeled her hyperfocus and sensory differences into an extraordinary ability to relate to animals and take in the world as they do, recognizing their cognitive and emotional abilities (Grandin & Johnson, 2004). Her sensitivity to animal suffering led to the design of systems for more humane treatment of livestock. She has also been an inspiration to so many who have been labeled with severe deficits by viewing many autistic symptoms, such as hyperspecificity, as strengths rather than weaknesses. Her visual

thinking allows her to find solutions that others might not see. She notes that whooping cranes can memorize long migratory routes they've flown only once by using a brain capacity similar to that shown by some individuals with autism in making complex drawings with perfect perspective. We need to see physical and cognitive differences in terms of *assets*, not only in terms of liabilities. By appreciating and enhancing each family member's interests and abilities, families can bring out their best and share joy in their bonds.