chapter 5 Mental Illness/Chemical Dependence

"Companion Demons"

[A father writes:] "Terry was dealt a doubly cruel hand: the companion demons depression and alcoholism. . . . After her teenage years the demons were always after her, relentlessly pulling at her stability and happiness. They took turns battering her with sadness and despair, which no doctor or medication seemed able to resolve. . . . Yet she persisted through countless AA meetings, numerous treatment facilities, hospitals, detox centers, and spiritual quests, and a thousand counseling sessions. . . . But in the end the demons won the physical battle and dragged her battered body to an untimely grave."

—George McGovern, Terry, xiii

Year after year after year. Hope does not spring eternal, but it may last a long time. There is a new medication, a highly recommended rehabilitation program, a therapist who really seems to care. But then the medication fails or the patient refuses to take it. The recovery doesn't last. The therapist is transferred. And the patient is back in the hospital, or detox center, or jail, or rooming house, or street. Meanwhile parents grow old, retire, die. Siblings graduate college, marry, divorce, start careers, change careers, travel, return. Children grow into adulthood and have children of their own. All of this happens in a world that those with severe mental illness or chemical dependence visit rarely, if at all.

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They may not recognize family members for a while, then suddenly recognize them all too well—lashing out in terrifying rages. They are on their own interior journey, insensible to the havoc they are causing in the lives of those who love-or remember having loved—them. Mental illness and chemical dependence are frequent but not inevitable partners. They are linked here because they share a common trajectory.

The first indication that something is wrong often appears in adolescence or early adulthood. Parents and siblings usually recall an intelligent, loving child who is transformed overnight into an unrecognizable stranger. Of her brother's first breakdown Elizabeth Swados writes: "The easiest way to understand his schizophrenia was to believe it didn't exist. My parents, worn out from advice, deeply concerned about their reputation in the community, preferred to suffer from the notion that there was something wrong with their son, but that he could fix it himself with the best medical help, discipline, and determination" (The Four of Us, 29).

Because adolescents and young adults are often unpredictable and prone to experimenting with different life-styles, the first breakdown is rarely recognized as the beginning of a long journey. As time passes, the authors comb through the past for danger signs they might have missed, even as they find comfort in the warming experiences they find there. George McGovern remembers Terry as a fun-loving daughter at play with her brothers and sisters. Jay Neugeboren remembers Robert as the younger brother who shared his childhood bedroom and dreams.

Adult children cherish early memories of a caring parent. If the onset of mental illness or chemical dependence is delayed but a decade, a mother or father has time enough to imprint a positive image. Christopher Dickey remembers a father who taught him about nature and poetry. Jackie Lyden has pictures of herself in the costumes her mother created for her. Tara Holley, whose birth coincided with her mother's first breakdown, is one of the few authors who has no memories of her own-so she borrows those of her aunts. Their reminiscences of her mother as a young vocalist on the cusp of success achieve iconic status in the life of the family, symbolizing all that it has lost.

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When it becomes clear that things are not going to get better on their own, authors embark on a search for aid. They have not yet exhausted their financial or emotional resources—which is fortunate, because the search is neither easy nor cheap. Private psychiatrists, hospitals, and rehab centers are the first port of call. With varying degrees of insight, the professionals suggest a course of treatment that promises hope for recovery. All that is asked of the patient and family is that they cooperate with the treatment plan laid out for them. Patients typically comply for a while; either they are in a setting that allows for no choice or they themselves believe in the possibility of cure. However, the constraints of treatment soon become clear—the disturbing side effects of medications, the therapy that seems to go nowhere, the call of a past life-style, a breakthrough of the illness—and they drop out.

Patients have begun their on-again, off-again relationship with the health care system. Their child, sibling, or parent may become unmoored but the family members hang on to the deck. At least for a while. They follow recommendations to different doctors, different approaches. They attend family groups. They learn a new language. Is the patient "a danger to herself or others?" Should they practice "unconditional acceptance" or "tough love"? They receive many opinions. At the time that Terry freezes to death on the snowbank onto which she has fallen in an alcoholic stupor, McGovern is following a counselor's advice that he be "less deeply involved" in her daily life. He never forgives himself.

Writing of her mother, Tara Holley sums up the problem: "I had tried everything I could think of to keep her off the street: temporary confinement in a hospital, halfway houses, motel rooms I paid for out of my own pocket. Nothing was ever settled: never could I tell myself, 'At last I've found the place'" (*In the Shadow of Schizophrenia*, 296).

As the years roll on, all but the very rich find they must turn to public agencies—state mental hospitals, public assistance, shelters—for help. Here they find a system of care that mirrors the chaotic and incomprehensible behavior of the patients. Understaffing, undertraining, and lack of interest are endemic. Psychiatrists are seen as rushed drug dispensers whose rare forays into psychological

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interpretation do more harm than good. Common problems with medication—such as oversedation or disturbing side effects—are ignored or changes prescribed without explanation. Social workers, counselors, and nurses receive more credit. Many are seen as offering concrete help and practical advice. They are appreciated for taking the time to listen and to offer human connection and support. But sooner or later they disappoint; hindered by large caseloads and insufficient resources, they are unable to follow through on their treatment plans. Moreover, there is a rapid turnover in such jobs, and the memoir author wearies of repeating the long, sad history of a loved one to each new worker.

The patient's ability to understand what is going on is not static: it ebbs and flows with the course of the disease and the effectiveness of the current treatment. Professionals may disagree on what level of awareness constitutes "competence," forcing caregivers to make unilateral decisions with no clear guidelines. Accepting the best of bad alternatives comes hard. Any illness can cause distressing physical changes in the patient. But the cumulative assaults of self-neglect and injury on the lives of the mentally ill and addicted are particularly harrowing for the authors to witness. Elizabeth Swados's brother careers through life with an amputated right leg and arm—suffered when he threw himself in front of a subway train many years before. Unwashed, reeking of body odor, he is not alone among the patients in this section. Some are described as gaunt. Others are toothless. Seeing them in such a state, unable even to make them comfortable and clean, symbolizes the powerlessness of the author.

To this burden is added the unanswerable question of cause. Parents feel that they must be to blame. Siblings wonder how they escaped. Adult children feel at risk. Since no one can tell them why this fate has befallen them, families come to their own conclusions. Society provides a ready-made list of reasons. What family tree does not have an alcoholic, mentally ill, or somewhat peculiar member somewhere in its branches? How many people reach adulthood without losing at least one beloved person to distance, divorce, or death? Who has grown up in a family devoid of conflict?

George McGovern turns up alcoholic relatives on his side of the family, his wife's postpartum depression after Terry's birth, and his

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own time away on the political trail while she was growing up. Remembering an early family life colored by his parents' unhappy marriage, Jay Neugeboren decides that his brother identified with the weaknesses of their parents while he identified with their strengths. Elizabeth Swados and Margaret Moorman do not seek reasons; they simply accept that that they must present a happy and "normal" face to the world—and so vindicate their parents' embarrassment over having a damaged child.

Adult children greet each year that passes with relief—the longer they live without developing symptoms of their parent's illness, the safer they feel. A few, like Tara Holley, seek the counsel of psychiatrists in reckoning the odds. More often, they act out their fears by life choices, recognizing the meanings of their actions only in retrospect. Christopher Dickey battens himself down: he marries and has a child while barely out of his teens. Jackie Lyden loosens her ties: she jumps on horseback and tours with a rodeo. By such decisive acts they claim control over their own lives, separating themselves from parents who are blatantly out of control.

The stories written by those who cared for the mentally ill or chemically dependent bear a stylistic resemblance. Less chronological, more circular, than memoirs of other illnesses, they reflect the need to reconcile healthy and sick images of their family member, to recapture all the positive moments and commemorate periods of normality. No matter how few they are in number, good memories prove crucial in sustaining the authors through the long decades that follow.

There is likely to be a changing cast of involved family members. Some drop out once and for all. Others come and go. Authors are often the only ones left to bear witness to the entire story. Eight years after her son's diagnosis, Swados's mother died of an overdose of sleeping pills. Neugeboren's mother, an active participant in her son's treatment for eight years—going so far as to run mental health fundraising events—decides, at the age of sixty-two, to move to Florida. "'I've done all I can do,' she said. 'Let the state take over. You be in charge from now on, Jay—I just can't handle it anymore'" (*Imagining Robert*, 20).

A few trips through the revolving door of the system and the meanings attached to the illness change. The mentally ill patient

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will not return to being the person once known. The chemically dependent patient will probably relapse. The health and social welfare system does not hold the magic key. The authors then begin the struggle to find a degree of separation that will allow them to live their own lives without abandoning their loved ones. An on-again, off-again pattern of involvement now emerges, reflecting the lifelong nature of the disease, the fact that the patient often rejects care, and a growing realization that no one person can be expected to shoulder all the burden. Sometimes it is the patient who pushes them away. Sometimes the authors, in the interests of their own mental health, find they must remove themselves from the scene. Yet it is always understood that one day the call that cannot be ignored will come. And they will return.

For those caregivers who cannot leave, the separation becomes internal. Like Tara Holley, whose mother is the homeless woman she passes each day on her way to college classes, they remain physically involved but their beliefs change. They begin to accept a situation that once would have been unthinkable. They stop looking to professionals for the answer. Now they look to the patient and to themselves.

As hopes for large changes fade, appreciation of small changes grows. Where caregivers once saw only failure, they now see a valiant struggle for survival. Tara Holley's mother sells flowers to motorists stopped at a traffic light. Elizabeth Swados's brother plays a harmonica, a cup for contributions at his feet. George McGovern's daughter sustains one eight-year period of sobriety in twenty-five years of adulthood. Jackie Lyden's mother uses her manic creativeness to start a mail order business. Aware of the difficulty that their loved ones have simply getting through each day, the authors view these efforts as triumphs.

By finding islands of normality in a sea of craziness, refusing to let the individuality of their loved ones be swept away in a tide of symptoms, many authors of the mental illness/chemical dependence experience sustain themselves through the years they are called upon to care.

There are two endings to the journey. A horrible death is, sadly, still common. The ambiguous character of many of these deaths—not intentional suicides but clear consequences of chemical dependence or

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