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The Legacy of Madness

"Lifetime of losses:" the hidden costs of growing up with a mentally ill parent

by [Lisa Lieberman](#) - December 30, 2004

Jon was in my tenth grade geometry class. For two semesters we sat catty-corner in Mrs. Hedrick's room doing proofs, comparing the sides of isosceles triangles, and pretending we'd never met. In fact, we'd known one another for years. Our mothers had spent time in the same mental hospital in the early '60s. Soulmates, they'd kept in touch through the years and every so often they'd set off on an escapade together. As kids, Jon and I got dragged along. By the time we hit high school, we'd shared more escapades than either of us cared to remember.

We'd both learned to compartmentalize: There was the weekday world of home and school where normalcy reigned. Our fathers had each remarried and formed new families; during the week we lived in orderly households. Weekends were another matter. On weekends we swapped our fathers' suburban routines for our mothers' bohemian fantasies, stability for spontaneity.

I'm guessing that Jon's mother was also bipolar -- not that we ever discussed our mothers' diagnoses, but they seemed wild in the same way. Laughing at things we didn't find funny, turning ordinary events into high drama, talking non-stop about inappropriate subjects, waylaying total strangers in the supermarket aisles, buttonholing sales clerks and gas station attendants, toll collectors, receptionists, and waiters to talk, talk, talk. At the very least it was embarrassing, being out in public with the two of them. And on occasion it was

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frightening, not knowing when or how the escapade would end.

Today there are support groups for family members, clearinghouses linking relatives of the mentally ill to community resources, strategies to help people cope. Jon and I coped on our own as best we could. The idea of supporting one another through the ups and downs of our mothers' mood disorders, of comparing notes, never occurred to us. Coping meant preventing the chaos of our weekend lives from wrecking the weekday fictions we maintained. It wasn't simply that we didn't want anybody at school to know that our mothers were crazy. Most of the time, we didn't want to admit it to ourselves.

Holidays were particularly difficult. The inability of a parent to be there, to be fully present when the whole world is celebrating is hard for children to understand. We all have expectations of what holidays should be about: turkey at Thanksgiving, eating latkes and playing the dreidel game at Chanukah, waking up Christmas morning to open presents under the tree. In school we learned all about traditions, but these seemed to apply to normal families, not ours.

My birthday generally falls during Chanukah, a double celebration that was always muted on account of my mother's illness. She tended to be in a depressed phase in December. There are good memories, but they're tinged with sadness. (Once, when my birthday fell on a Saturday, we spent the entire day watching television and eating Sugar Daddies in her bed.)

I've talked to other adult children of mentally ill parents and they report similar blues around the holidays. Going to visit relatives, for instance, could become unmanageable. "I remember my father going through this ritual where we all had to get into the car and then wait for him to close up the house," says "Susan." "He would be booby trapping things, putting a thread across the door and stacking pennies in a certain way so that if somebody came in they'd knock them over."

Her life was circumscribed by her father's paranoia. Christmas was when she felt most isolated because her father, who is white, was convinced that other white people were conspiring against him. Guests would be subjected to cross-examination. Bringing a boyfriend home was sheer agony. "We stopped seeing people because he would be so rude," she says.

For "Carol," whose grandmother and uncle were bipolar, "holidays carried the potential for great pain." Her mother kept a distance from her mentally ill mother and brother, so Carol only saw them on special occasions, like birthdays, Christmas and Thanksgiving. Watching her uncle deteriorate over the years was a poignant experience. "When I was younger," she says, "he was the fun and fun-loving uncle. As he got older, he'd either be noticeably depressed -- almost catatonic -- or he'd be so up and manic that no one else could get a word in edgewise."

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"We manage to save ourselves in the end. Everyone does," writes NPR correspondent Jacki Lyden in *Daughter of the Queen of Sheba*, her memoir of growing up with a manic-depressive mother. But this salvation is achieved at a cost. As adults, we bear the wounds of our unstable childhoods. The scars are visible if you know where to look: unresolved fears and inadmissible anger, the bottomless reservoir of guilt, the shame we cannot shed, no matter how confident we may seem. We stand apart, burdened with responsibilities we did not choose, anxieties we cannot shake; marked by our experiences in ways that we may not always like but find difficult to change. We cope as best we can.

In high school I was not cool: didn't drink, never tried drugs -- and this was in the early 70s -- hung out with smart guys, gay guys. Safe guys, in other words. I joke about it now. "I'm the most aggressively sane person you'll ever meet," I tell acquaintances, still sensitive about my uncoolness. Of course, I was terrified of turning out like my mother, of losing control. Physically, we are so alike, she and I. Everyone commented on our resemblance. I inherited her dark hair and eyes, her slender build. Did I inherit her problem as well?

Children of the mentally ill live with the fear that we may be genetically prone to our parents' disorders. Some play it safe, as I have done, afraid to take risks, afraid that if we let ourselves go too much we might succumb to the family curse. Others choose not to have children, worried about passing on the genes for the disease. Such fears are not unfounded. Recent studies show that close relatives of people with bipolar disorder, schizophrenia, or major depression are more likely to develop these diseases than the average person, but scientists haven't succeeded in isolating the genes involved in the transmission of even the most common disorders.

The genetic brew is too complex, and so we're left to worry and watch ourselves for the slightest signs of our parents' illnesses. At the same time, we're afraid to acknowledge the illnesses, afraid that we'll be judged on the basis of their disorders -- as the daughter of a schizophrenic father or the son of a depressed mother. Given the stigma that still surrounds mental illness in our society, who would want to be defined in that way?

Naming a family member's disease, "sharing the worst of it," says Jane Moser, is crucial to putting the illness into perspective and getting on with our lives. I met with Moser, former president of the Western Mass. chapter of the National Alliance for the Mentally Ill (NAMI), in the organization's rabbit warren of offices above an Italian bakery in Agawam. NAMI is a grassroots organization founded by families of people with severe mental illnesses that funds research and provides support, education, and advocacy in communities across the country. Every state has affiliates; there are 1,200 local chapters across the United States and Canada, in Puerto Rico and American Samoa.

"I do think NAMI offers this unique kind of support that can say, 'We've been there, we understand where you are and what it's like and how painful it has

been," says Moser. A large part of NAMI'S mission, she says, is to remove the shame that accompanies mental illness -- the embarrassment that prevented Jon and me from talking in high school.

Since its founding in 1979, the organization has been committed to educating the public about the physiological causes of mental illness. If disorders such as depression, schizophrenia, and manic-depression are the result of a brain dysfunction, then they are no different from any other disease. Every piece of literature that NAMI disseminates carries this statement: *Severe mental illnesses are biologically based brain disorders*. "It is freeing if you can say, 'My oldest son has a mental illness,' just as we might say, 'Our oldest son has diabetes,'" says Moser.

Learning to live with a family member diagnosed with a severe mental illness is in some ways like receiving a diagnosis of a chronic and debilitating physical illness. There are similar phases -- denial, anger, bargaining, acceptance -- and similar stresses as the household becomes governed by the ill person's needs. In such a situation, the needs of the healthy members of the family can easily be overlooked.

Catherine Simon's mother was diagnosed with schizophrenia. "I felt angry because she was so needy and couldn't take care of me," she says. Ruth Ehrenberg remembers her father waking her up in the middle of the night when she was young to ask if she could help him find the recording devices that were planted throughout the house. Shortly after this incident, he was diagnosed with schizophrenia and Ehrenberg was sent to an orphanage. At 64, after a career spent as a psychotherapist helping others come to terms with the pain of damaged childhoods, Ehrenberg's pain is still palpable. "My father had been a source of great, great love for me when I was growing up," she says. "I lost him."

Simon and Ehrenburg are both members of the Freedom Center, a group founded in 2001 by Pioneer Valley residents diagnosed with severe mental illness who challenge the biomedical model of mental illness (the notion that people labeled as schizophrenic can be compared to diabetics, that taking psychiatric medication is just like taking insulin). Where NAMI is mainstream enough to work with mental health providers, members of the Freedom Center find themselves in an adversarial relationship with the system because they challenge the prevailing medical model of psychiatric illness, including the assumptions that mental illness is a disease and that medication is the best or only form of treatment.

Simon describes her sadness, as a child, at seeing her mother's personality disappear under medication. "All the things I loved about her were no longer there," she says. Ehrenburg, who now cares for a beloved grandson diagnosed in college as schizophrenic, grew frustrated with the system's unwillingness to consider holistic alternatives to the psychiatric drugs that weren't working in her

grandson's case. "It was terrifying to me to have spent my life in a helping profession only to have this door slammed in my face," she says.

Both NAMI and the Freedom Center provide support that cannot be gotten elsewhere, and maybe their different approaches are a good thing. Support is not one-size-fits-all, and the value of sharing experiences with others who have been through what you are going through cannot be overstated. As Ehrenburg acknowledges, it is not just the act of listening that helps people, it's the curiosity behind it. "Someone wants to know who you are," she says. "That makes you realize you're worth getting to know."

Unfortunately, the mental health system provides little help for families of the mentally ill. Clinicians recognize that when any member of a family is seriously ill, the entire family system is disrupted, and this is true whether the illness is physical or mental. Yet only rarely are the needs of children in families with any kind of illness addressed. Unless they are having a diagnosable problem, insurance companies won't pay for therapy. In addition, families with one mentally ill member may not want to believe that their apparently healthy children are having problems as well, especially when everyone is intent on pretending (in public, at least) that things are okay.

When Clea Simon applied to Harvard, her parents told her to say that she was an only child. Simon's older brother and sister were diagnosed with schizophrenia and had little contact with the family by that time. In her memoir, *Mad House*, she talks about the guilt that accompanied the denial of her siblings' existence. "Once my brother and sister had left home," she writes, "no new acquaintances knew of their existence unless we consciously made the effort to inform them, and while my parents' code of silence isolated me in some ways, it also protected me from the curious and the cruel." Only now does Simon see the price she paid for colluding in her parents' silence: "I found that I couldn't open up to the present -- not if I still kept other parts of myself closed down."

Coming to terms with a family member's mental illness is a lot like grieving the death of someone we loved. We've lost that person because they have withdrawn into depression or into their delusions. A parent who was once attentive has disappeared, replaced by someone who is sad or unstable. The mother who used to tuck us into bed at night is unable to leave her own bed. The father who used to tell us stories is trapped inside one of his stories. "Adult children of parents who have a mental illness describe a lifetime of losses," writes Julie Tallard Johnson in *Hidden Victims*. "The primary distinction between mental illness and death is that mental illness is not recognized as a significant loss."

My mother cycled between yearly episodes of mania and less severe periods of depression. I'd lose her, then find her, only to lose her again. Early in my teens I stopped looking and took on the responsibility of mothering her instead. I was not always the most sensitive of caretakers. I yelled at my mother for not getting

help, for not trying lithium, which I'd read was successful in treating manic-depression. I tried to prevent her from drinking when she was high, watched her like a hawk when she was low. Our relationship, even during her stable periods, deteriorated; she is no longer in my life.

Caretakers have come in for a fair amount of criticism in recent years. We are viewed as manipulative and controlling, obsessed with another person's problems and oblivious to our own, guilty, dishonest, and resentful. "Codependent" is the term for people like me. It is not a nice term. Codependents are seen as part of the problem that substance abusers and mentally ill people face. Our desire to rescue prevents the addict or the ill person from exercising control over his or her own life; our "enabling" makes self-destructive behavior worse. But as Melody Beattie writes in her 1987 bestseller, *Codependent No More*, many of us were victims, true victims, of parental neglect or abuse: children who didn't get enough love for ourselves, but who managed to get satisfaction from being the parent we needed.

When I had my own children, I was able to stop parenting my mother. There are times when I mourn the loss of her in my life. She has never met her grandchildren and to them, I suspect, she is more like a character in a story than a real person: the mother who went away and never quite came back. I wish that it were different. I wish that she could have acknowledged her problems and sought some kind of help for herself when I was young. For that matter, I wish that I could have acknowledged her problems and sought help for myself earlier, before the damage to our relationship became irreparable. Her absence, then and now, is a gap in my life that cannot be filled. I cope as best I can.

Lisa Lieberman is the author of Leaving You: The Cultural Meaning of Suicide (Ivan R. Dee, 2003).

NAMI-Western Massachusetts serves residents of Franklin, Hampshire and Hampden counties. For more information, call 1-800-295-2121 or visit their website: <http://members.aol.com/amiwma>. The national organization features a special community for the adult children of parents with mental illnesses. Go to www.nami.org and click on "Online Communities." The Freedom Center offers support and advocacy for individuals diagnosed with severe mental illness who seek greater self-determination: www.freedom-center.org.

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