Expert on Mental Illness Reveals Her Own Fight

See the original story plus a short video, in the New York Times.

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HARTFORD — Are you one of us?

The patient wanted to know, and her therapist — Marsha M. Linehan of the University of Washington, creator of a treatment used worldwide for severely suicidal people — had a ready answer. It was the one she always used to cut the question short, whether a patient asked it hopefully, accusingly or knowingly, having glimpsed the macramé of faded burns, cuts and welts on Dr. Linehan's arms:

"You mean, have I suffered?"

"No, Marsha," the patient replied, in an encounter last spring. "I mean one of us. Like us. Because if you were, it would give all of us so much hope."

"That did it," said Dr. Linehan, 68, who told her story in public for the first time last week before an audience of friends, family and doctors at the Institute of Living, the Hartford clinic where she was first treated for extreme social withdrawal at age 17. "So many people have begged me to come forward, and I just thought — well, I have to do this. I owe it to them. I cannot die a coward."

No one knows how many people with severe mental illness live what appear to be normal, successful lives, because such people are not in the habit of announcing themselves. They are too busy juggling responsibilities, paying the bills, studying, raising families — all while weathering gusts of dark emotions or delusions that would quickly overwhelm almost anyone else.

Now, an increasing number of them are risking exposure of their secret, saying that the time is right. The nation's mental health system is a shambles, they say, criminalizing many patients and warehousing some of the most severe in nursing and group homes where they receive care from workers with minimal qualifications.

Moreover, the enduring stigma of mental illness teaches people with such a diagnosis to think of themselves as victims, snuffing out the one thing that can motivate them to find treatment: hope.

"There's a tremendous need to implode the myths of mental illness, to put a face on it, to show people that a diagnosis does not have to lead to a painful and oblique life," said Elyn R. Saks, a professor at the University of Southern California School of Law who chronicles her own struggles with schizophrenia in "The Center Cannot Hold: My Journey Through Madness." "We who struggle with these disorders can lead full, happy, productive lives, if we have the right resources."

These include medication (usually), therapy (often), a measure of good luck (always) — and, most of all, the inner strength to manage one's demons, if not banish them. That strength can come from any number of places, these former patients say: love, forgiveness, faith in God, a lifelong friendship.

But Dr. Linehan's case shows there is no recipe. She was driven by a mission to rescue people who are chronically suicidal, often as a result of borderline personality disorder, an enigmatic condition characterized in part by self-destructive urges.

"I honestly didn't realize at the time that I was dealing with myself," she said. "But I suppose it's true that I developed a therapy that provides the things I needed for so many years and never got."

'I Was in Hell'

She learned the central tragedy of severe mental illness the hard way, banging her head against the wall of a locked room.

Marsha Linehan arrived at the Institute of Living on March 9, 1961, at age 17, and quickly became the sole occupant of the seclusion room on the unit known as Thompson Two, for the most severely ill patients. The staff saw no alternative: The girl attacked herself habitually, burning her wrists with cigarettes, slashing her arms, her legs, her midsection, using any sharp object she could get her hands on.

The seclusion room, a small cell with a bed, a chair and a tiny, barred window, had no such weapon. Yet her urge to die only deepened. So she did the only thing that made any sense to her at the time: banged her head against the wall and, later, the floor. Hard.

"My whole experience of these episodes was that someone else was doing it; it was like 'I know this is coming, I'm out of control, somebody help me; where are you, God?' " she said. "I felt totally empty, like the Tin Man; I had no way to communicate what was going on, no way to understand it."

Her childhood, in Tulsa, Okla., provided few clues. An excellent student from early on, a natural on the piano, she was the third of six children of an oilman and his wife, an outgoing woman who juggled child care with the Junior League and Tulsa social events.

People who knew the Linehans at that time remember that their precocious third child was often in trouble at home, and Dr. Linehan recalls feeling deeply inadequate compared with

her attractive and accomplished siblings. But whatever currents of distress ran under the surface, no one took much notice until she was bedridden with headaches in her senior year of high school.

Her younger sister, Aline Haynes, said: “This was Tulsa in the 1960s, and I don’t think my parents had any idea what to do with Marsha. No one really knew what mental illness was.”

Soon, a local psychiatrist recommended a stay at the Institute of Living, to get to the bottom of the problem. There, doctors gave her a diagnosis of schizophrenia; dosed her with Thorazine, Librium and other powerful drugs, as well as hours of Freudian analysis; and strapped her down for electroshock treatments, 14 shocks the first time through and 16 the second, according to her medical records. Nothing changed, and soon enough the patient was back in seclusion on the locked ward.

“Everyone was terrified of ending up in there,” said Sebern Fisher, a fellow patient who became a close friend. But whatever her surroundings, Ms. Fisher added, “Marsha was capable of caring a great deal about another person; her passion was as deep as her loneliness.”

The door to the room where as a teenager Dr. Linehan was put in seclusion. The room has since been turned into a small office.

A discharge summary, dated May 31, 1963, noted that “during 26 months of hospitalization, Miss Linehan was, for a considerable part of this time, one of the most disturbed patients in the hospital.”

A verse the troubled girl wrote at the time reads:

They put me in a four-walled room

But left me really out

My soul was tossed somewhere askew

My limbs were tossed here about

Bang her head where she would, the tragedy remained: no one knew what was happening to her, and as a result medical care only made it worse. Any real treatment would have to be based not on some theory, she later concluded, but on facts: which precise emotion led to which thought led to the latest gruesome act. It would have to break that chain — and teach a new behavior.

“I was in hell,” she said. “And I made a vow: when I get out, I’m going to come back and get others out of here.”

Radical Acceptance

She sensed the power of another principle while praying in a small chapel in Chicago.

It was 1967, several years after she left the institute as a desperate 20-year-old whom doctors gave little chance of surviving outside the hospital. Survive she did, barely: there was at least one suicide attempt in Tulsa, when she first arrived home; and another episode after she moved to a Y.M.C.A. in Chicago to start over.

She was hospitalized again and emerged confused, lonely and more committed than ever to her Catholic faith. She moved into another Y, found a job as a clerk in an insurance company, started taking night classes at Loyola University — and prayed, often, at a chapel in the Cenacle Retreat Center.

“One night I was kneeling in there, looking up at the cross, and the whole place became gold — and suddenly I felt something coming toward me,” she said. “It was this shimmering experience, and I just ran back to my room and said, ‘I love myself.’ It was the first time I remember talking to myself in the first person. I felt transformed.”

The high lasted about a year, before the feelings of devastation returned in the wake of a romance that ended. But something was different. She could now weather her emotional storms without cutting or harming herself.

What had changed?

It took years of study in psychology — she earned a Ph.D. at Loyola in 1971 — before she found an answer. On the surface, it seemed obvious: She had accepted herself as she was. She had tried to kill herself so many times because the gulf between the person she wanted to be and the person she was left her desperate, hopeless, deeply homesick for a life she would never know. That gulf was real, and unbridgeable.

That basic idea — radical acceptance, she now calls it — became increasingly important as she began working with patients, first at a suicide clinic in Buffalo and later as a researcher. Yes, real change was possible. The emerging discipline of behaviorism taught that people could learn new behaviors — and that acting differently can in time alter underlying emotions from the top down.

But deeply suicidal people have tried to change a million times and failed. The only way to get through to them was to acknowledge that their behavior made sense: Thoughts of death were sweet release given what they were suffering.

“She was very creative with people. I saw that right away,” said Gerald C. Davison, who in 1972 admitted Dr. Linehan into a postdoctoral program in behavioral therapy at Stony Brook University. (He is now a psychologist at the University of Southern California.) “She could get people off center, challenge them with things they didn’t want to hear without making them feel put down.”

No therapist could promise a quick transformation or even sudden "insight," much less a shimmering religious vision. But now Dr. Linehan was closing in on two seemingly opposed principles that could form the basis of a treatment: acceptance of life as it is, not as it is supposed to be; and the need to change, despite that reality and because of it. The only way to know for sure whether she had something more than a theory was to test it scientifically in the real world — and there was never any doubt where to start.

Getting Through the Day

"I decided to get supersuicidal people, the very worst cases, because I figured these are the most miserable people in the world — they think they're evil, that they're bad, bad, bad — and I understood that they weren't," she said. "I understood their suffering because I'd been there, in hell, with no idea how to get out."

In particular she chose to treat people with a diagnosis that she would have given her young self: borderline personality disorder, a poorly understood condition characterized by neediness, outbursts and self-destructive urges, often leading to cutting or burning. In therapy, borderline patients can be terrors — manipulative, hostile, sometimes ominously mute, and notorious for storming out threatening suicide.

Dr. Linehan found that the tension of acceptance could at least keep people in the room: patients accept who they are, that they feel the mental squalls of rage, emptiness and anxiety far more intensely than most people do. In turn, the therapist accepts that given all this, cutting, burning and suicide attempts make some sense.

Finally, the therapist elicits a commitment from the patient to change his or her behavior, a verbal pledge in exchange for a chance to live: "Therapy does not work for people who are dead" is one way she puts it.

Yet even as she climbed the academic ladder, moving from the Catholic University of America to the University of Washington in 1977, she understood from her own experience that acceptance and change were hardly enough. During those first years in Seattle she sometimes felt suicidal while driving to work; even today, she can feel rushes of panic, most recently while driving through tunnels. She relied on therapists herself, off and on over the years, for support and guidance (she does not remember taking medication after leaving the institute).

Dr. Linehan's own emerging approach to treatment — now called dialectical behavior therapy, or D.B.T. — would also have to include day-to-day skills. A commitment means very little, after all, if people do not have the tools to carry it out. She borrowed some of these from other behavioral therapies and added elements, like opposite action, in which patients act opposite to the way they feel when an emotion is inappropriate; and mindfulness meditation, a Zen technique in which people focus on their breath and observe their emotions come and go without acting on them. (Mindfulness is now a staple of many kinds of psychotherapy.)

In studies in the 1980s and '90s, researchers at the University of Washington and elsewhere tracked the progress of hundreds of borderline patients at high risk of suicide who attended weekly dialectical therapy sessions. Compared with similar patients who got other experts' treatments, those who learned Dr. Linehan's approach made far fewer suicide attempts,

landed in the hospital less often and were much more likely to stay in treatment. D.B.T. is now widely used for a variety of stubborn clients, including juvenile offenders, people with eating disorders and those with drug addictions.

“I think the reason D.B.T. has made such a splash is that it addresses something that couldn’t be treated before; people were just at a loss when it came to borderline,” said Lisa Onken, chief of the behavioral and integrative treatment branch of the National Institutes of Health. “But I think the reason it has resonated so much with community therapists has a lot to do with Marsha Linehan’s charisma, her ability to connect with clinical people as well as a scientific audience.”

Most remarkably, perhaps, Dr. Linehan has reached a place where she can stand up and tell her story, come what will. “I’m a very happy person now,” she said in an interview at her house near campus, where she lives with her adopted daughter, Geraldine, and Geraldine’s husband, Nate. “I still have ups and downs, of course, but I think no more than anyone else.”

After her coming-out speech last week, she visited the seclusion room, which has since been converted to a small office. “Well, look at that, they changed the windows,” she said, holding her palms up. “There’s so much more light.”