THIRTY years ago, I was given a diagnosis of schizophrenia. My prognosis was "grave": I would never live independently, hold a job, find a loving partner, get married. My home would be a board-and-care facility, my days spent watching TV in a day room with other people debilitated by mental illness. I would work at menial jobs when my symptoms were quiet. Following my last psychiatric hospitalization at the age of 28, I was encouraged by a doctor to work as a cashier making change. If I could handle that, I was told, we would reassess my ability to hold a more demanding position, perhaps even something full-time.

Then I made a decision. I would write the narrative of my life. Today I am a chaired professor at the University of Southern California Gould School of Law. I have an adjunct appointment in the department of psychiatry at the medical school of the University of California, San Diego, and am on the faculty of the New Center for Psychoanalysis. The MacArthur Foundation gave me a genius grant.

Although I fought my diagnosis for many years, I came to accept that I have schizophrenia and will be in treatment the rest of my life. Indeed, excellent psychoanalytic treatment and medication have been critical to my success. “Medication have been critical to my success. Indeed, excellent psychoanalytic treatment and medication have been critical to my success. Indeed, excellent psychoanalytic treatment and medication have been critical to my success.”

Conventional psychiatric thinking and its diagnostic categories say that people like me don’t exist. Either I don’t have schizophrenia (please tell that to the delusions crowding my mind), or I couldn’t have accomplished what I have (please tell that to U.S.C.’s committee on faculty affairs). But I do, and I have. And I have undertaken research with colleagues at U.S.C. and U.C.L.A. to show that I am not alone. There are others with schizophrenia and such active symptoms as delusions and hallucinations who have significant academic and professional achievements.

Over the last few years, my colleagues, including Stephen Marder, Allison Hamilton and Amy Cohen, and I have gathered 20 research subjects with high-functioning schizophrenia in Los Angeles. They suffered from symptoms like mild delusions or hallucinatory behavior. Their average age was 40. Half were male, half female, and more than half were minorities. All had high school diplomas, and a majority either had or were working toward college or graduate degrees. They were graduate students, managers, technicians and professionals, including a doctor, lawyer, psychologist and chief executive of a nonprofit group.

At the same time, most were unmarried and childless, which is consistent with their diagnoses. (My colleagues and I intend to do another study on people with schizophrenia who are high-functioning in terms of their relationships. Marrying in my mid-40s— the best thing that ever happened to me— was against all odds, following almost 18 years of not dating.) More than three-quarters had been hospitalized between two and five times because of their illness, while three had never been admitted.

How had these people with schizophrenia managed to succeed in their studies and at such high-level jobs? We learned that, in addition to medication and therapy, all the participants had developed techniques to keep their schizophrenia at bay. For some, these techniques were cognitive. An educator with a master’s degree said he had learned to face his hallucinations and ask, “What’s the evidence for that?” Or is it just a perception problem?” Another participant said, “I hear derogatory voices all the time... You just gotta blow them off.”

Part of vigilance about symptoms was “identifying triggers” to “prevent a fuller blown experience of symptoms,” said a participant who works as a coordinator at a nonprofit group. For instance, if being with people in close quarters for too long can set off symptoms, build in some alone time when you travel with friends.

Other techniques that our participants cited included controlling sensory inputs. For some, this meant keeping their living space simple (bare walls, no TV, only quiet music), while for others, it meant distracting music. “I’ll listen to loud music if I don’t want to hear things,” said a participant who is a certified nurse’s assistant. Still others mentioned exercise, a healthy diet, avoiding alcohol and getting enough sleep. A belief in God and prayer also played a role for some.

One of the most frequently mentioned techniques that helped our research participants manage their symptoms was work. “Work has been an important part of who I am,” said an educator in our group. “When you become useful to an organization and feel respected in that organization, there’s a certain value in belonging there.” This person works on the weekends too because of “the distraction factor.” In other words, by engaging in work, the crazy stuff often recedes to the sidelines.

Personally, I reach out to my doctors, friends and family whenever I start slipping, and I get great support from them. I eat comfort food (for me, cereal) and listen to quiet music. I minimize all stimulation. Usually these techniques, combined with more medication and therapy, will make the symptoms pass. But the work piece—using my mind— is my best defense. It keeps me focused, it keeps the demons at bay. My mind, I have come to say, is both my worst enemy and my best friend.

THAT is why it is so distressing when doctors tell their patients not to expect or pursue fulfilling careers. Far too often, the conventional psychiatric approach to mental illness is to see clusters of symptoms that characterize people. Accordingly, many psychiatrists hold to the view that treating symptoms with medication is treating mental illness. But this fails to take into account individuals’ strengths and capabilities, leading mental health professionals to underestimate what their patients can hope to achieve in the world.

It’s not just schizophrenia: earlier this month, the Journal of Child Psychology and Psychiatry posted a study showing that a small group of people who were given diagnoses of autism, a developmental disorder, later stopped exhibiting symptoms. They seemed to have recovered—though after years of behavioral therapy and treatment. A recent New York Times Magazine article described a new company that hires high-functioning adults with autism, taking advantage of their unusual memory skills and attention to detail.

I don’t want to sound like a Pollyanna about schizophrenia; mental illness imposes real limitations, and it’s important not to romanticize it. We can’t all be Nobel laureates like John Nash of the movie “A Beautiful Mind.” But the seeds of creative thinking may sometimes be found in mental illness, and people underestimate the power of the human brain to adapt and to create.

An approach that looks for individual strengths, in addition to considering symptoms, could help dispel the pessimism surrounding mental illness. Finding “the wellness within the illness,” as one person with schizophrenia said, should be a therapeutic goal. Doctors should urge their patients to develop relationships and engage in meaningful work. They should encourage patients to find their own repertory of techniques to manage their symptoms and aim for a quality of life as they define it. And they should provide patients with the resources—therapy, medication and support—to make these things happen.

“Every person has a unique gift or unique self to bring to the world,” said one of our study’s participants. She expressed the reality that those of us who have schizophrenia and other mental illnesses want what everyone wants: in the words of Sigmund Freud, to work and to love.”

Elyn R. Saks is a law professor at the University of Southern California and the author of the memoir “The Center Cannot Hold: My Journey Through Madness.”
Memoir About Schizophrenia Spurs Others to Come Forward

By BENEDICT CAREY

Researchers have long wondered how some people with schizophrenia can manage their symptoms well enough to build full, successful lives. But such people do not exactly line up to enroll in studies.

For one thing, they are almost always secretive about their diagnosis. For another, volunteering for a study would add yet another burden to their stressful lives.

But that is beginning to change, partly because of the unlikely celebrity of a fellow sufferer. In 2007, after years of weighing the possible risks, Elyn R. Saks, a professor of law at the University of Southern California, published a memoir of her struggle with schizophrenia, “The Center Cannot Hold.” It became an overnight sensation in mental health circles and a best seller, and it won Dr. Saks a $500,000 MacArthur Foundation “genius” award.

For psychiatric science, the real payoff was her speaking tour. At mental health conferences here and abroad, Dr. Saks, 56, attracted not only doctors and therapists, but also high-functioning people with the same diagnosis as herself — a fellowship of fans, some of whom have volunteered to participate in studies.

“She’s in the audience and she starts to self-disclose, or sometimes I would be on a panel with someone” who had a similar experience, Dr. Saks said. She also received scores of e-mails from people who had read the book and wanted to meet for lunch. She told many of them about the possibility of participating in a research project.

She now has two studies going, one in Los Angeles and another in San Diego, tracking the routines and treatment decisions of these extraordinary people. The movie producer Jerry Weintraub has optioned the book.

It has been a remarkable response, considering that the book was almost abandoned. Dr. Saks surveyed friends and colleagues for years before publishing it and got very mixed advice. Her husband was against it; the risks were too high. Academic colleagues warned her that coming out with a disorder as serious as schizophrenia could only harm her. “You want to be known as the schizophrenic with a job?” one said.

Her friend Stephen Behnk, director of ethics at the American Psychological Association, was
supportive of her decision. “I remember talking about it just on the cusp of when she was going to send off the manuscript,” Dr. Behnke said. “I said that we needed to sit down and make sure she was ready for this. It was like she was about to jump off of a cliff.”

Jump she did. With the MacArthur money, she founded the Saks Institute for Mental Health Law, Policy and Ethics to study mental health and society. She is now working on another book, “Mad Women: A Most Uncommon Friendship,” with the author Terri Cheney, who has written about her struggles with bipolar disorder.

“I was very lucky, being in academia, where people have been very accepting of this,” Dr. Saks said. “Most people struggling to manage a severe mental illness do not have the luxury to do what I did.”
Elyn R. Saks: Mind matters

Her book about life as a schizophrenic, "The Center Cannot Hold: My Journey Through Madness," is as ferocious and droll as Saks herself. Her expertise has been earned quite literally from the inside out.

January 29, 2011 | Patt Morrison


Saks deserves her laughs. The lawyer and law professor, author, MacArthur "genius" grant winner and head of USC's Saks Institute for Mental Health Law, Policy and Ethics has been on that couch -- and has probably hidden under it. Her book about life as a schizophrenic, "The Center Cannot Hold: My Journey Through Madness," is as ferocious and droll as Saks herself. Her expertise has been earned quite literally from the inside out.

It makes perfect sense that roller skating, complete with nimble turnarounds and hypnotic intensity, is Saks' sport of choice. And that she has insights to share about the still-unfolding events in Tucson.

What was your reaction to the Arizona shootings and the speculation about the mental health of the alleged killer, Jared Lee Loughner?

It was a very rough ride -- extremely traumatic, extremely tragic.

[If you don't] admit that you're ill or you need help, and then you do something totally horrific, [that] drastically increases stigma, which in turn increases people's unwillingness to get help. And for those of us who suffer with mental illness, every time someone with mental illness does something dangerous, it kind of tars us in a way that it shouldn't.

I think the media is doing a better job with this than it has with other [such events], contextualizing the violence, reporting [mental illness] success stories, but the nature of the beast [is] people are afraid of someone different. I think we should have a public discussion about mental illness and criminality and civil commitment and resources. As tragic as the [Tucson] story is, maybe it will call attention to mental health.

A few decades ago, people with alcoholism or senility were locked up in mental hospitals. Surely things have improved?

I think things have gotten better. Back in the '60s, certain policies led to opening large warehousing mental hospitals. A lot of people say lawyers really screwed things up by [then] releasing [patients] into the streets. I see it a little differently. I see our country not having the political will to do the right thing.

Some people say I'm unique, that there aren't other people with schizophrenia like me. Well, there are people like me out there, but the stigma is so great that they don't come forward. It's easy for me. I have tenure, I have a secure position, I work at a wonderful place, but there is a lot of stigma.

People told me I should do [the book] under a pseudonym. I thought that sent the wrong message. So I did it under my own name, and I've gotten a really wonderful reception.

What are some of the myths about schizophrenia?

That's a common myth that schizophrenia means split personality. The schizophrenic mind is not so much split as shattered. I like to say schizophrenia is like a waking nightmare. [When you're having a nightmare] you've got all the bizarre images and impossible things happening, and you're terrified, but then you just sit bolt upright in bed and the experience dissipates. No such luck with a schizophrenic episode -- you can't just open your eyes and make it go away.

There's a debate over how hard it should be to even briefly commit someone against his will. It's hard to do in California, easier in Arizona.

I think by the [Arizona] standards, [Loughner] was committable. People just didn't take the steps, for unknown reasons. The father [said], "I don't know how this happened." [Perhaps] the school thinks the police will do it. The parents think the school will do it. And then people feel like it's too awful to commit somebody, they may be afraid of revenge -- there's all sorts of reasons. And there's the very realistic [concern] that [they] may lose all influence over this person. Working to get people on board with a treatment is much better than force. I was restrained 20 hours at a time. I was forcibly medicated. It was a nightmare. I'm pro-psychiatry, but I'm very anti-force. We should listen to the patients. If we get people to want treatment, that's the best guarantee that they're going to take treatment.

A bunch of my work has been on the capacity to consent to or refuse treatment, and that to me is the line: whether the person lacks or has capacity. And it's a fine line. I certainly don't believe it's never appropriate to use force or coercion. I just think we should have tools to help
people buy into it, so we don't have to subject them to trauma and humiliation.

We need more resources so people can do well. Mine is not the story of a lone woman who overcame odds. Enormous treatment resources were invested, five-day-a-week psychotherapy for decades, great psychopharmacology, wonderful friends and family, a supportive work environment. I'm not saying that everybody [with schizophrenia] can be a professor, but most people I think can live up to their "potential."

That sounds intensive and expensive. I don't think this country would spend that kind of money on mental healthcare.

But we might be able to study things that are less expensive and [are still] efficacious. We need to be thoughtful and resourceful.

We tend to operate on the Ford Pinto model -- we'll take a calculated risk and let something potentially dangerous stay out there, until something bad happens, and then we just deal with the immediate problem, not the underlying one.

The only way to prevent these extremely low-probability events is just tie everybody up. You can't really predict it, [and] the cost of never having [it] happen is that we all lose a lot of liberty.

What happens if research ultimately finds all these mental disorders are genetic or bad brain wiring?

People could feel more sympathetic to the patient -- that it's physical, totally out of their control and not their fault. On the other hand, people could feel more helpless -- that this is something hardwired, that there's nothing you can do about it.

There are so many movies that deal with mental illness -- "The Snake Pit," "Marnie," "One Flew Over the Cuckoo's Nest," even a "Terminator," with the heroine locked up as delusional. What do you make of these?

Some are good, some are not so good. Sometimes I see movies that make [mental hospitals] seem like summer camp. And then there's "falling in love with the therapist and life gets better," which does a disservice. [In reality] there was no roommate [in mathematician John Nash's story, "A Beautiful Mind"] -- that was just a cinematic device that personified his thoughts.

On the other hand, entertainment [is] a way to get across something that is real. "A Beautiful Mind" did a good job, apart from that roommate thing. I thought it was very clever, the way they brought you into his delusional world, and only well into it do you see what it is.

How has the pharmacology changed?

The meds have gotten much better. I resisted for years the idea that I had mental illness or schizophrenia. I had all these convoluted explanations, and the way to prove that I wasn't [mentally ill] was to get off medication, so I would try with great gusto and miserably fail.

My analyst said: "You're spending all of your time fighting the medication and the diagnosis. You need space for your professional life, your personal life." I got on continuous medication and then switched to the new meds, and it was like daylight dawning after a dark night. Suddenly I could see the world clearly. I had a fantasy that everybody's mind contained the chaos mine did -- they were just more polite about saying it out loud. And then I took this medication and thought, huh, maybe everybody else doesn't have the chaotic, violent thoughts that I used to have. It made me realize that I had the illness, but it also made the illness define me less.

I get lots of e-mails -- probably the prime thing people ask is, how do I get my mother/brother/spouse to take medication? I encourage them to go to the National Alliance on Mental Illness website. There are some good books for families. A lot of people with mental illness are in denial, so you've got to get the person to accept that they have a mental illness.

Like the start of a 12-step program?

Right, but I disagree with that. You can say, "I understand you don't think you have a mental illness, but you're complaining about sleeplessness or agitation, and this pill will help with that. Why don't you give it a try?" You don't force humiliation on them, but you get them to want to take treatment. It doesn't work all the time.

If you're diagnosed with cancer, you probably tell the doctor to throw everything at it. But with mental illness, that's not always the reaction.

I [used to] say, "I don't want to use a crutch," but then I thought, if my foot were broken, I'd use a crutch. Aren't my neuro-transmitters entitled to gentle, kind and caring treatment too? So I totally got over the "narcissistic" injury of being mentally ill and needing medication, and now it's like, whatever works. [The poet Rainer Maria] Rilke said, "Don't take away my devils, because my angels will leave too." I say my angels have already fled; I'll take the pill in a heartbeat.

The insanity defense may come up in the Arizona case. How should that defense figure in criminal cases in general?

It's not going to be a popular thing to say, but we should take more account of mental health issues, at least when we sentence people. There should be some mitigation for someone who was really struggling.

Are there words being used that you can't stand to hear?

People who would never dream of using an ethnic or racial slur talk about nutcases, wackos, loony tunes, and people all the time say, "Oh, he's crazy," and it's hurtful, it really is hurtful. I don't know what we should be called. The PC lingo is [mental health] "consumer," which makes mental health services sound like getting a car serviced, but I really don't have a better word. We're not supposed to use "patient" anymore. People don't like it.
Did your book revealing your schizophrenia change your relationships?

Probably. Mostly for the better. It's not really nice to have a big secret; it's nice to be able to say what you're feeling and thinking and not worry. One of the funniest e-mails I got [was from] this guy who said, "Professor Saks, you and the doctors are all wrong, you actually are a space alien and the medication has poisoned [you]."

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This interview was edited and excerpted from a longer taped transcript. Interview archive: latimes.com/pattasks.
Infiltrating the Enemy of the Mind

Jay Neugeboren

The Center Cannot Hold: My Journey Through Madness
by Elyn R. Saks
Hyperion, 340 pp., $24.95

Twenty-seven years old and in her first semester at Yale Law School, Elyn Saks had days when, she writes,

I feared that my brain was actually heating up and might explode. I visualized brain matter flying all over the room, spattering the walls. Whenever I sat at a desk and tried to read, I caught myself putting my hands up to either side of my head, trying to hold it all in.

She was especially concerned, should this happen, about who might get hurt. “The innocent bystander problem,” she notes (italics in original).

The fear did not go away. A few weeks into the semester, after gibbering away on the roof of the law school—believing both that people are out to kill her and that she has killed others (“Don’t try to f**k with me, Richard,” she tells a friend, “I’ve killed better men than you.”)—she is taken to Yale–New Haven Hospital where she surrenders her telephone-wire belt and a roof nail, after which, she writes, “it was all over.”

Within seconds, The Doctor and his whole team of goons swooped down, grabbed me, lifted me out of the chair, and slammed me down on a nearby bed with such force that I saw stars. Then they bound both my legs and arms to the metal bed, with thick leather straps.

While in restraints, Elyn is force-fed an antipsychotic drug—the first she has ever had. Transferred by ambulance to Yale Psychiatric Institute, she asks that a blanket be put over her face so nobody can see her. “Maybe,” she thinks, “this is what it feels like to be dead” (italics in original).

There is a long tradition, published and unpublished, of first-person accounts of madness—from John Perceval, Daniel Paul Schreber, and Vaslav Nijinsky to William Styron, Kay Redfield Jamison, and Andrew Solomon—but of those I’m familiar with, Elyn Saks’s The Center Cannot Hold is the most remarkable of all. I know of no other account that, by its recall of each moment of short- and long-term crises, allows us to begin to experience what being in this condition must be like and feel like to the person suffering it.

“As frightened as I was,” she writes,
I was equally angry, and frantic to find a way to show defiance. So I inhaled as deeply as I could, and started belting out some beloved Beethoven. Not, for obvious reasons, “Ode to Joy,” but rather Beethoven’s Fifth Symphony. BABABA BA! BABABA BA!…

For hours, I sang it and shouted it and hollered it with all the power remaining inside me. I fought off the beings who were attacking me, I yanked against the restraints, and I sang my heart out. Every once in a while, a nurse came by with another little demitasse of antipsychotic liquid. I swallowed it passively, then fought to swim above the fog it created. BABABA BA!

Elyn is transferred to Yale’s Psychiatric Evaluation Unit, where she jabbers away at her psychiatrist, Dr. Kerrigan, confiding that she used to be God (but was demoted), telling him she has killed hundreds of thousands of people with her thoughts. He tells her he thinks it “a good idea” for her to spend more time in restraints. “We believe they help patients feel safe, more in control,” he says.

Two weeks later, for the first time in her life, Elyn receives a diagnosis: “Chronic paranoid schizophrenia with acute exacerbation.” Her prognosis is listed as “grave,” the staff believing that her “next hospitalization would be measured in years, not weeks or months.”

I’d always been optimistic that when and if the mystery of me was solved, it could be fixed; now I was being told that whatever had gone wrong inside my head was permanent and, from all indications, unfixable…. For the rest of my life. The rest of my life. It felt more like a death sentence than a medical diagnosis.

In addition, she discovers that the Psych Unit, without her permission or knowledge, has informed the law school that she will not return that year, or possibly ever.

Although Elyn has had bizarre thoughts and hallucinations since childhood (believing that buildings talked to her, seeing a man coming at her with a knife when no man is there), and although she’s known that her behavior has often been unacceptable, she has also believed that “everyone thought this way”—scrambled, hallucinatory, paranoid, destructive—the difference being that others were better at masking the thoughts, “much as everyone passes gas, but not in company.”

Before the episode at Yale, Elyn (who grew up in North Miami: “my family was solidly in the middle class, and as time went on, our means increased”) had spent time in a rehab center as a teenager (for smoking pot), had finished first in her class at Vanderbilt University, had been a Marshall Scholar at Oxford University, had been hospitalized twice for floridly psychotic episodes, and had, for two years, undergone a five-times-a-week psychoanalysis.

But the analysis, which she believes saved her life, has, during her hospitalizations at Yale, accustomed her to express herself in ways that cause difficulties. “Any expression of anything that I was feeling,” she writes, “fear, anguish, restlessness, disorganized and delusional thoughts—led to immediate restraints.”

Part of the problem is that she has been behaving like a patient in psychoanalysis—saying exactly...
what’s on her mind, no matter how crazy it sounds. “That was how analysis worked,” she explains. “That was the point. Otherwise, how would [my analyst] know what was going on inside me? But the people at [Yale] didn’t want to know.”

While Elyn tells the story of her life in beautifully observed detail, she also steps outside it to become the most trustworthy of participant-observers, and to provide us with an ongoing and shrewd commentary on the ways we have, historically, treated people with severe mental illnesses, and the rationales and efficacies of these treatments.

Thus, at Yale, she is able to extrapolate from her own experience to describe a familiar and deadly “classic bind” for most psychiatric patients:

They’re struggling with thoughts of wanting to hurt themselves or others, and at the same time, they desperately need the help of those they’re threatening to harm. The conundrum: Say what’s on your mind and there’ll be consequences; struggle to keep the delusions to yourself, and it’s likely you won’t get the help you need.

From Yale, Elyn goes to the Institute of Pennsylvania Hospital, where she remains hospitalized for the rest of the academic year. In May, she returns home briefly, then travels to England, where, throughout the summer, she sees her analyst, Mrs. Jones, three times a week. In the fall she reenrolls at Yale Law School.

Although Elyn will, during the next quarter-century (she is now fifty-two), suffer several major psychotic episodes, she will never again be hospitalized for psychiatric reasons. She will also, if with occasional lapses, come to accept the fact that she is schizophrenic and that she will probably have to take antipsychotic medications for the rest of her life. Whenever, “believing that the less medication I took, the less defective I was,” she stops taking them, she relapses severely. She will also continue, year upon year, three, four, and five times a week, in psychoanalysis.

Despite debilitating side effects of medications (including early signs of tardive dyskinesia, a movement disorder caused by antipsychotic medications), despite acute psychotic episodes and the fear of their recurrence, despite major medical problems (breast cancer, brain hemorrhages, a hysterectomy, and the removal of her ovaries following the appearance of warning signs of ovarian cancer), and despite repeated confirmation by doctors of a diagnosis of schizophrenia, Elyn continues to achieve at the highest levels. She graduates from Yale Law School (where she becomes an editor of the *Yale Law Journal*) and goes on to teach at the University of Southern California Law School, where she is appointed the Orrin B. Evans Professor of Law, Psychiatry, and the Behavioral Sciences. She’s also appointed an adjunct professor of psychiatry at the University of California, San Diego, School of Medicine (“I’ve infiltrated the enemy!” she announces to a friend). She publishes numerous articles and several books, becomes a research clinical associate at the New Center for Psychoanalysis. She falls in love and marries.

She has those things that, in her words, “make life wonderful—good friends, a satisfying job, loving
relationships”—but that very few people with schizophrenia ever have. She is an “exception to a lot of rules,” she knows, and much of her good fortune is about luck—“about the ticket I drew in the lottery: parents with resources, access to trained and talented professionals, and a frequently unattractive stubborn streak that’s worked in my favor as often as it has against me.”

Her exceptional intelligence has contributed mightily to her ability to survive:

My brain was the instrument of my success and my pride, but it also carried all the tools for my destruction…[for] if the fire that burned me signaled my destruction, it was also the same fire that got me out of bed in the morning and sent me to the library even on the most frightening days.

But central to her ability both to survive and to thrive, she believes, have been two things: medications and—rare in the chronicles of schizophrenia—psychoanalysis.

While medication had kept me alive,” she writes, “it had been psychoanalysis that had helped me find a life worth living.” In a passage one might post on the door of every psychiatrist who believes patients can live by medications alone, she explains:

Medication has no doubt played a central role in helping me manage my psychosis, but what has allowed me to see the meaning in my struggles—to make sense of everything that happened before and during the course of my illness, and to mobilize what strengths I may possess into a rich and productive life—is talk therapy. People like me with a thought disorder are not supposed to benefit much from this kind of treatment, a talk therapy oriented toward insight and based upon a relationship. But I have. There may be a substitute for the human connection—for two people sitting together in a room, one of them with the freedom to speak her mind, knowing the other is paying careful and thoughtful attention—but I don’t know what that substitute might be. It is, at the heart of things, a relationship, and for me it has been the key to every other relationship I hold precious. Often, I’m navigating my life through uncertain, even threatening, waters—I need the people in my life to tell me what’s safe, what’s real, and what’s worth holding on to.

The prevailing view, beginning with Freud, is that when it comes to schizophrenia, psychoanalysis and most forms of talk therapy invariably cause relapse and regression. As Saks notes, Freud believed that psychosis was too narcissistic, too inward-looking, to allow the patient to develop a transference relationship with the analyst, and without that transference, there would be no grist for the psychoanalytic mill.

There have been dissenters, especially in the decades immediately following World War II (among them Frieda Fromm-Reichman, Otto Will, Harold Searles, and Otto Kernberg). More recently, especially given the ascendancy of evidence-based medicine and its emphasis on “recovery”—on
measurable reduction of symptoms that provides evidence of improvement—analysis and talk therapy have plummeted from favor.²

An influential article that reviews two decades of the relevant literature, for example (one often cited to me by psychiatrists), concludes by proposing “a moratorium on the use of psychodynamic treatments for schizophrenia.”³ In Surviving Schizophrenia: A Family Manual, E. Fuller Torrey writes that psychoanalysis is to schizophrenia as Laetril is to cancer. Both have enjoyed surprising popularity considering the fact that they lack scientific basis, are completely ineffective, and still attract persons who are willing to pay vast sums of money for a cure.

“Successful treatment,” Torrey declares, “means the control of symptoms,” and this view prevails in the American Psychiatric Association’s Practice Guideline for the Treatment of Patients with Schizophrenia (2004), where the only type of talk therapy recommended is the brief, “evidence-based practice” of cognitive behavioral therapy (CBT), a short-term form of psychotherapy created by Aaron Beck, himself trained as a psychoanalyst, which—his novel contribution—emphasizes the role of conscious thought processes in mental disorders. By identifying and addressing negative beliefs, thought processes, and behaviors independent of unconscious conflicts and replacing them with positive beliefs, Beck and his colleagues discovered, patients could become capable of developing effective skills with which to cope with their problems.

In the final report of the President’s Freedom Commission on Mental Health, the emphasis, to the exclusion of all traditional forms of talk therapy (supportive psychotherapy, psychodynamic psychotherapy, insight-oriented psychotherapy, etc.), is on medication, on improving and disseminating evidence-based practices, and on short-term forms of psychotherapy such as CBT and interpersonal psychotherapy.

But consider what happens to someone suffering from schizophrenia for whom neither medications nor short-term therapies lead to a reduction in symptoms sufficient to make recovery possible. Consider, that is, the usual alternative: what treatment—and life—is like for most people who suffer from mental illness, and who do not have Elyn’s luck or intelligence, her will or her wherewithal.

Schizophrenia affects about three million Americans (approximately 1 percent of the population worldwide), yet despite our progress in research and treatment, Elyn writes, “recent statistics indicate that only one in five people with schizophrenia can ever be expected to live independently and hold a job.”

Like Elyn, my brother Robert was a bright young man (winning a New York State Regents scholarship to college) who was diagnosed at nineteen as a chronic paranoid schizophrenic. Like Elyn, he thrived on talk therapy. Chosen during his first long-term hospitalization to participate in insight-oriented psychotherapy three times a week for nine months, Robert was able to recover sufficiently to live independently in New York City, and to complete his second year of college. But when he relapsed and was rehospitalized, and rehospitalized repeatedly—more than fifty times in the ensuing decades—he came to spend most of his years in state hospitals (our family’s wherewithal
being well below that of Elyn’s), where he received abundant medications and no talk therapy at all.

During these years he deteriorated terribly, and when, in 1997, thirty-five years after his first hospitalization, he was transferred to Bronx Psychiatric Center, it was the consensus of the staff that even were he able one day to live outside a locked ward, he was destined to be repeatedly rehospitalized.

At Bronx State, however, the director of psychology, Dr. Alvin Pam, disagreed with the staff, and saw him as a candidate for supportive psychotherapy in which the therapist worked with Robert to enable skills that would prove helpful in the present, while helping him make realistic plans for the future. For most of the next two years, Robert met with a therapist once a week, and once again he thrived. He was discharged after two years, and for the ensuing eight years he was not hospitalized for even an hour for emotional or psychiatric reasons.

Despite living, during these years, in two excellent group homes in the Hell’s Kitchen section of New York City, where the staff at each residence has been kind, devoted, and attentive, the quality of his life has declined steadily. Largely due to side effects of antipsychotic medications, his physical condition has become grave: he has gained an enormous amount of weight, he has major cardiac and pulmonary problems, and he suffers from drug-induced Parkinsonism (trembling hands, shuffling feet, drooling, diminished impulse control). To counteract the Parkinsonian symptoms, he must take drugs that blunt the effectiveness of the antipsychotic medications, one result being that he is, by turns, lethargic and agitated, irritable and bored, and often, especially to staff, nasty.

While medications may reduce symptoms, what, for a person who has lived for any extended period of time with madness, of the fear and the shame, the isolation and the feelings of worthlessness that invariably accompany madness? And what is it like, day after day and year after year, to be treated essentially as a set of symptoms that must be managed?

When, several years after his discharge from Bronx State, Robert’s irritability reached levels that left him inconsolable and the staff at his group home exasperated (and threatening him with expulsion), I asked the staff psychiatrist if it were possible for Robert to talk with somebody—once a week, or once every other week—and said that Robert was eager for talk therapy. Having somebody to talk to might also provide a practical dividend by giving him a place to vent his anger, and to deal with behavior and obsessions that were making life for him and the staff increasingly difficult. The answer Robert and I received was the same we’d received from this psychiatrist several years earlier: “No resources.”

Elyn writes movingly of her first analytic therapy with Mrs. Jones, who believed people with psychosis could benefit from analysis. “It was her theory,” Elyn writes, “that psychotic individuals are filled with (even driven by) great anxiety, and that the way to provide relief is to focus directly on the deepest sources of that anxiety.”

The story of Elyn’s relationship with Mrs. Jones is as poignant a tale of the healing powers of the doctor–patient relationship—of the difference that “tolerance, patience, and understanding” can make in a vulnerable, wounded person’s life—as one is likely to find. “For two straight years, I did my
work,” Elyn writes, “met my obligations, made it through the day as best I could, and then fled to Mrs. Jones, where I promptly took the chains off my mind and fell apart.”

Is there an evidence-based way to measure the benefits to someone suffering the pain of psychosis of feeling free to simply let go—to let symptoms, along with aberrant, wild, destructive, and shameful thoughts, fly—and to trust that when you do, you won’t be punished or stigmatized or brutalized? On several occasions when Elyn’s analysts recommended that she go to the hospital and she refused, they didn’t, Elyn has recently written in private correspondence, “take the easy way out and require me to go. They tolerated a good deal of anxiety by doing that, but it was a great gift to me.” Among the benefits of letting go, Elyn notes, is seeing that others can be tolerant of “the bad in you”—of what you’re ashamed of—and that this “in itself makes people feel safer.”

When, several years later, Mrs. Jones died after being badly injured in an automobile accident, “the grief at her loss burrowed deep into my soul,” Elyn writes. “This was, in every way that mattered, a death in the family. For so long, through everything that had happened to me, I’d taken courage in knowing that Mrs. Jones was there, in her house, in that office. She knew me like no other.”

Elyn is eloquent about the crucial importance to one’s well-being of being known. “One of the worst aspects of schizophrenia,” she writes, “is the profound isolation—the constant awareness that you’re different, some sort of alien, not really human.” Hospitalized for the first time during her stay in Oxford, Elyn thinks:

> What was happening to me? Why had it happened? And who would help me? But no one came. 

> No one will ever come, I thought. I am worthless, I cannot even control my own mind. Why would anyone want to save me?

Conversely, at Yale, when friends come by, she is “both comforted and moved that they’d come at all.” She shows a friend the leather straps used to tie her to the bed, and he winces and shakes his head. “He got it,” she writes.

> And that gave me courage. It was so easy to feel isolated and alone here; each one of these people who cared enough about me to come and visit gave me reason to hope that I was worth saving.

Medication and talk therapy may allay the terrible feelings of isolation that accompany schizophrenia, “but friendship,” she writes, “can be as powerful as either.”

Elyn continues, to this day, to have difficult times and psychotic flare-ups, but the love and companionship that come with friendship, and with her marriage to Will, get her through. “Sometimes, even now, when I’m going into an episode,” she writes,

> I don’t tell [Will]—not to keep secrets, but so as not to burden him. Nevertheless, he almost always knows. He can tell from my silence—or a certain kind of silence. It’s a gift to have someone know me so well.
Robert’s cousins and former friends, dozens of them, often ask about him, but during the eight years he’s been living in New York City, outside hospitals, I can count on the fingers of one hand the number of visits he has had from these friends and cousins. In this, alas, Robert is not alone, for I almost never, even on weekends, see visitors in the residences in which he’s been living.

Many chronic illnesses and disabilities—heart disease, diabetes, multiple sclerosis, emphysema—require lifelong medication and treatment, and, often, housing in special facilities—but rarely do these conditions carry with them the lifelong penalty that comes with mental illness: isolation from the ordinary world, and from those who have known us. “When you have cancer,” Elyn writes, “people send flowers; when you lose your mind, they don’t.”

The Nobel Prize–winning neuroscientist Eric Kandel has written that when he began his residency in psychiatry fifty years ago, he “sensed that psychoanalysis could be immeasurably enriched by joining forces with biology,” and that if “the biology of the twentieth century were to answer some of the enduring questions about the human mind, those answers would be richer and more meaningful if they were arrived at in collaboration with psychoanalysis.” He goes on to articulate the basis for his ongoing optimism:

I believed then, and I believe more strongly now, that biology may be able to delineate the physical basis of several mental processes that lie at the heart of psychoanalysis—namely, unconscious mental processes, psychic determinism (the fact that no action or behavior, no slip of the tongue is entirely random or arbitrary), the role of the unconscious in psychopathology (that is, the linking of psychological events, even disparate ones, in the unconscious), and the therapeutic effect of psychoanalysis itself. What particularly fascinated me, because of my interest in the biology of memory, was the possibility that psychotherapy, which presumably works in part by creating an environment in which people learn to change, produces structural changes in the brain and that one might now be in a position to evaluate those changes directly.

But Kandel’s optimism remains just that: a hope for the future, since we cannot yet describe or evaluate the structural changes he alludes to. Still, he is impressed by the results cognitive behavioral therapy has produced in people suffering from chronic mental disorders. Although such therapy often achieves results, especially with respect to depression, he adds, “the improvement is not always long-lasting.”

Indeed, it would appear, Kandel writes, that for some patients to achieve sustained improvement, short-term modes of psychotherapy (fewer than twenty sessions) such as CBT, “interpersonal psychotherapy,” “brief dynamic psychotherapy,” and “transference psychotherapy,” all of which derive from psychoanalysis, must continue for one or two years, perhaps because treating symptoms of their disorder “without addressing the underlying conflicts is not always efficacious.”

In the meantime, what we know, with CBT as with psychoanalysis, is that some treatments, whether evidence-based or not, and whether psychological or pharmaceutical or a combination of the two, work for some people, and that some don’t. We are, that is, far from having adequate answers to the
treatment of psychoses, though in many instances, a happy set of convergences—of medications and therapists—can bring about beneficial results that transcend the usual, pessimistic prognostications. What is clear from Elyn’s life, as from Robert’s, then, is that to deprive patients of the possibility of extended talk therapy is to deprive them of treatment that not only may be helpful psychiatrically, but that can, in lives more isolated and meager than Elyn’s or Robert’s, be a source of comfort, meaning, and well-being.

Elyn Saks may be anomalous in many ways—in her will, her illness, her treatment, her luck, and her exceptional gifts—but she is not anomalous in her own sense of human experience, and one great virtue of her book is that it reminds us of what, to use her words, makes our lives worth living. She makes us aware, that is, of the sources of health and happiness—of resilience—within us, even in the darkest of times. “Whenever I was out someplace and heard people laughing together,” she writes at a time when she feared she might never be well or happy again,

I’d turn toward the sound in much the same way a flower turns to the sun. To laugh, to tease; not to be afraid of saying or doing something stupid or clumsy, because even if you did, you’d be loved anyway, and you’d always know it. What might it be like, to be completely at home in one’s life, and not be alone?

Letters

*The Enemy of the Mind*: An Exchange May 29, 2008

1 My brother Robert was hospitalized, put in a straitjacket, and force-fed medications when he had a psychotic episode similar to Elyn's. He was nineteen years old at the time. In a subsequent hospitalization, he was frequently placed in isolation, twenty-four hours a day, day after day, in a room that contained only a sheetless bed and an empty dresser. This was called "reduced stimulation" by his doctor, who informed me that "in retrospect patients come to appreciate the reduction in stimulation—the limits and boundaries that have been set for them." ↩

2 Evidence-based medicine attempts to assess the quality of evidence relevant to risks and benefits of treatment (including lack of treatment). The term first appeared in medical literature in 1992; the most common definition is David Sackett's: "Evidence-based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett et al., "Evidence-Based Medicine: What It Is and What It Isn't," *British Medical Journal*, Vol. 312, No. 7023 (1996), pp. 71–72). One problem, when evidence-based medicine is applied to chronic mental illness, is that it is easier to measure—to quantify—symptoms and symptom reduction, and, thus, the efficacy of medications, than it is to measure intangibles that, in often grim, unenviable lives, pertain to quality of life, however diminished the quality of those lives may be. ↩


4 On her wedding day, alone with her closest friend, Steve, she writes that "a serious question had been troubling me for hours, and finally I just had to ask it. "Will aliens be attending the reception?"" Steve holds her hand, tells her that they won't, and she tells us that she "needed to hear that reassurance from him, and having heard it, I happily went on with the day." ↩

SAN FRANCISCO — Dressed in a blue power suit, Elyn Saks addressed a gathering of psychologists here with the quiet demeanor of an intellectual sure of her academic resume: college valedictorian, Oxford scholar, Yale law student, USC legal professor.

But her words were not serene. They evoked nightmares.

Over 30 years, as she forged her career, she wrestled with uncouth visions, violent commands and suicidal impulses, Saks explained to her listeners. In her worst moments, the TV made fun of her, ashtrays danced and walls collapsed. Sure she was a witch, she burned herself as punishment with cigarettes, lighters and electric heaters. She believed she was single-handedly responsible for the deaths of thousands of people. The brains of close associates were taken over by aliens.

Fearful of rejection, she told no one about her inner strife, other than her doctors and closest friends, even as she was hospitalized, force-fed anti-psychotic drugs and lashed to metal gurneys. She became an exhibit, she recalled, a specimen, "a bug impaled on a pin and helpless to escape."

In her gravelly voice, Saks detailed for the psychologists how she became convinced that her former psychotherapist was a monster, how she needed to protect herself. Before one therapy session, Saks went to a hardware store to look at axes.

Still, she feared the therapist would abandon her, Saks told the audience, revealing her thoughts that back then raced toward a plot: I will kidnap her and keep her tied in my closet. I will take good care of her. I will give her food and clothes. She will always be there when I need her to give me psychoanalysis.

She was able to keep most of her delusional episodes private. "I couldn't control what I thought," she said. "But I could usually control what I said."

Saks has schizophrenia, a severe mental disorder often characterized by social isolation, disorganized speech, delusions and hallucinations. She has defied the prediction of a doctor who once said she would never lead an independent life. She has even flourished, thanks to a strict regimen of medication and talk therapy.

Now she wants to dash the myths surrounding an illness that affects 3 million Americans: Schizophrenics aren't all emotionally out of touch, shouting and swiping at gremlins, shut away in hospitals. Like her, some lead productive lives with good friends, loving spouses and precious emotional triumphs.

At 51, Saks says, the time has come to reveal her secret. The San Francisco speech was one of her first major public forays.

Like the story of fellow schizophrenic John Forbes Nash, the Nobel Prize-winning economist and mathematician whose life was portrayed in the book and film "A Beautiful Mind," Saks' life illustrates not only the stresses mental illness places on personal and professional relationships but also how they can be overcome.

The disease emerged when Saks was a child in Miami in the 1960s. There were little quirks: She couldn't leave her bedroom until her shoes were lined up. She slept only after she had arranged her books just so.

She suffered night terrors, sure a murderer lurked outside her window. She read Sylvia Plath's novel, "The Bell Jar," and identified with the protagonist's descent into madness.

One day, at age 16, Saks impulsively fled school in terror. On the five-mile walk home, houses began sending her messages: Look closely. You are special. You are especially bad. Look closely and ye shall find.

Her delusions followed her to Vanderbilt University, where she frightened dorm-mates, quacking like a duck and swallowing a bottle of aspirin. "Schizophrenia," she would later say, "rolls in like a slow fog, becoming imperceptibly thicker as time goes on."

As a coping mechanism, Saks submerged herself in her schoolwork. "Tall, geeky and socially uneasy," as she describes herself then, she lost weight, existing on coffee, cigarettes, cheese sandwiches or bowls of tomato soup.

She said little in class. But Saks' academic papers often floored professors with their insights. While she was still a student, her elegant but troubled mind already worked with the acuity of a practiced academic.

Years later, when she was a Marshall scholar studying philosophy at Oxford University, Saks' disease tightened its grip. She often walked...
the streets, gesticulating and muttering to herself. But she would not talk to others.

It's wrong to talk. Talking means you have something to say. I have nothing to say. I am nobody, a nothing.

Admitted to a local psychiatric hospital, she insisted she was not sick and refused to take any medications. Then one day, Saks had a revelation: She looked into the mirror. And she recoiled.

"It felt as if someone had punched me in the stomach," she later wrote. "Good God, I thought. Who is that? I was emaciated and hunched over like someone three or even four times my age. My face was gaunt; my eyes were simultaneously vacant and full of terror. . . . It was the visage of a crazy person on the long-forgotten back ward of a hospital for lunatics."

She knew the person in the mirror needed help. So she agreed to start taking anti-depressants. But she was still years from realizing the true nature of her problems.

Medicated, Saks resumed her Oxford studies. She also began seeing a specialist in Kleinian analysis, a treatment advocating that patients unleash their fantasies during sessions.

One of Saks' delusions, known as Capgras syndrome, leads victims to believe close acquaintances have been replaced by identical-appearing impostors. "I know you say you are my analyst," she told her psychotherapist. "But I also know the truth. You are an evil monster, perhaps the devil. I won't let you kill me. You are evil, a witch. I'll fight."

She graduated from Oxford in 1981, her secret double life still intact. She was on medication, but like many who suffer from mental illness, she was inconsistent in taking her pills and would stop once her brain storms settled.

While studying law at Yale years later, Saks landed in another psychiatric ward after complaining that someone had infiltrated her research. She also alarmed study mates when she climbed out a window to dance on the law library roof.

The New Haven hospital staff was harsh: Unlike the ones in Britain, staffers force-fed her drugs and roughly strapped her to gurneys. During the speech before the psychologists, she detailed her unruly thoughts at the time.

Did you know I was God? But I'm not anymore. What I am now, I can't tell you. Have you killed anyone? I've killed hundreds of thousands with my thoughts. It's not my doing. Someone acts through my brain. I give life and I take it away.

Her medication increased, she began to level off and prepared to return to law school, reading her legal textbooks in the psychiatric ward's day room.

I'm a law student, not a mental patient. I want my life back, damn it! And if I have to bite my tongue until it bleeds, I am going to get it back.

One day, Saks did something she'd never done before: Over slices of pizza with fellow first-year law student Steve Behnke, she finally opened up about the debilitating delusions and how it felt to be tied down against your will.

"Elyn had this enormous burden," Behnke said. "Her mind has been very good to her and very bad to her."

Emboldened by Behnke's support and her continued therapy, Saks pursued the issue of mental illness as a detective would, investigating the demons in herself and others. She researched the complex civil issues in mental health law, such as involuntary commitment and the insanity defense. As part of her law school training, she represented psychiatric patients charged with crimes in local courts.

While researching a paper on the use of mechanical restraints in psychiatric wards, Saks mentioned to a professor how such devices could be both frightening and demeaning to patients.

He dismissed the notion. "You don't really understand," he said. "These people are different than you and me. It doesn't affect them the way it would affect us."

Even today, Saks shudders at those words. "He saw people like me as being less valuable, defective," she said. "The idea that psychiatric patients would be insensitive to pain and harm. I wish I'd had the strength in my illness to say something."

At times, her outer and inner worlds collided. At one seminar on representing psychiatric patients, a professor played a tape of an interview of a man who had killed his parents.

Saks recognized him: He'd been a fellow patient at the New Haven hospital. She left the room, feeling she would violate his privacy to listen.

"When you have cancer, people send flowers. When you lose your mind, they don't."

It's a little wisdom Behnke told Saks. By then, in 1999, she'd been teaching law at USC for a decade. Suddenly, she was diagnosed with breast cancer. Friends sent bouquets as she began radiation therapy.

The stress of the cancer sent her into another spiral. She talked about little green people.

The radiation was successful, but the episode eventually led to another epiphany: She could no longer write off her episodes as fits of
depression. She realized that she was schizophrenic, which meant she needed not only her continued talk therapy but also her antipsychotic medications for the rest of her life.

The admission unlocked a door.

During those years, she also began to better understand the societal implications of those suffering from schizophrenia.

She became an adjunct professor of psychiatry at the UC San Diego School of Medicine, visiting several times a year to conduct research. She wrote books dealing with society's rejection of the mentally ill.

Saks became associate dean for research at USC's Gould School of Law. In 2001, she married a witty former law librarian named Will Vinet, who brought humor to her life, made her watch cartoons to keep her laughing and helped her remain ever-watchful for the stress-induced triggers of psychotic episodes: a gloomy quietness or desire to sit alone inside a darkened room.

For Saks, the time had come for a more forthright approach: to write about mental illness as a patient, not as a professor. After all, who else knew more about the loneliness and confusion of the psych ward?

Deciding to write a book, she began to reexamine her life. She sent for her medical records in Britain and New Haven and took classes in memoir writing.

But Saks knew she might pay a price for her candor. Would her hard-earned career come crashing down if people knew the real workings of her mind?

A colleague suggested that Saks write under a pseudonym. But that would send the wrong message, Saks explained.

"Elyn," her colleague reasoned, "do you want to be known as a schizophrenic with a job?"

Saks did have her doubts. Even while properly medicated, she still harbors several irrational thoughts each day, but she manages to dismiss the obsessions. Would the parents of former students call, wanting to know how USC could keep a schizophrenic professor on its staff? Would she get hate mail?

Before the book was published, she called the law school dean. "When this book comes out, is the university going to stand behind me?" she asked. The university has given her project full support.

On Aug. 14, Saks’ memoir, "The Center Cannot Hold: My Journey Through Madness," was published. The secret was out.

As she prepared to address the American Psychological Assn. convention, Saks fidgeted.

"I'm nervous," she said.

Her book had received positive reviews. But there were hints of negativity: One USC worker told Saks she would have never gone to dinner with her had she known of her schizophrenia, afraid that one of Saks' delusional episodes could occur at any time.

Saks was speaking to her first large audience since her memoir had been published. She was never comfortable with public speaking, and her hands shook visibly as she took the podium, introduced by her old friend Steve Behnke.

When she finished, a lone woman rose to her feet, followed by more audience members. Quickly, the entire crowd was standing. The applause was prolonged and emotional as listeners lined up to speak with her.

Saks knows the battle isn’t over. There are relapses. On her wedding day, stress caused her to ask: "Will aliens be attending the reception?"

But there is hope for the future. A new generation of drugs, along with five-times-a-week therapy, keeps her grounded. She avoids stress. Basking in emotional support, Saks gives it as well: When she hears about a friend suffering emotional turmoil, she sends them flowers.

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