

A Burden to Be Well

Sisters and Brothers of the Mentally III

by Karen Brown

The devastating effects of mental illness have been well documented in films, books, and academia. But until recently there has been little said about the sisters and brothers of the mentally ill. Now researchers are starting to look at what they're calling the "well-sibling" syndrome.

In families where mental illness hits early, the entire household feels the impact.

"We're not having any more soup! Eat it or don't have any!" says mother Deb Stanas as her daughter screams. "Listen, Olivia," Deb pleads, "either take what you have or don't have any." A spoon clangs on floor. Deb tells Olivia to pick it up. Olivia screams, "No!"

Apparently this is a relatively calm afternoon at the Stanas household in southern New Hampshire. Eight-year-old Olivia is bounding between the kitchen, where she's demanding a snack from her mother, and the living room, where her two sisters are doing homework and playing computer games. Two years ago, Olivia was diagnosed with bipolar disorder, an illness characterized by debilitating highs and lows, and outbursts of violence. Suddenly, Olivia accuses her 11-year-old sister Audrey of taking her toy, and her mother tells Audrey to go to her room.



Olivia (right) with sister, Rose. Photo by Karen Brown

Audrey asks, "Do you know what a baby she's being? ... She slapped Rose a minute ago. She slapped me a minute ago." Deb replies, "You know better than to do that," as Olivia continues screaming.

"Olivia sets the tone in the house," says Deb. "When she's having a bad day, we're all having a bad day. It's next to impossible not to feed off that irritability, that anxiety, that anger."

Deb says it's been torture for Audrey.

On this afternoon, Audrey has just gotten off the school bus. She makes herself Ramen noodles and relishes having her mother all to herself. It's a half-hour before Olivia gets home. As Audrey eats, she recalls the time Olivia's outburst sent her to the emergency room.

"She started calling me a name," says Audrey, "and next thing I know, she says, 'I'm going to throw this book at you,' and I turned around and it hit my face. And it was bleeding. And I remember screaming down the hall and watching the blood drip down my face. I don't believe she ever got grounded for that."

Deb Stanas is well aware of the resentment Audrey feels - that her childhood is, in many ways, at the mercy of Olivia's volatility. For a short time, they took Audrey to a counselor, but it didn't seem to help.

"She was so angry," says Deb. "She was threatening suicide. 'I'm going to run away. I hate this family. I can't live here.' And to be quite honest, what she went through, I can't blame her. She really got abused by this child, and I couldn't separate them. I felt so helpless. I couldn't protect her."

Deb says she does try to keep Audrey safe from Olivia. She puts them on opposite ends of the house. But as soon as she turns her back, Olivia runs to find her sister. Deb installed a lock on the door, but Olivia found the key.

"They should have her locked in the laundry room again," says Audrey. "That worked."

Her mother is actually relieved that Audrey can be so blunt, like a typical child, because she worries Audrey's growing up too fast.

That's why she and her husband try to give Audrey days when she's the center of attention. At a cheerleading tournament, Audrey and a friend were selected to sing the national anthem. The whole family watched, even Olivia, in the packed auditorium.

Deb worries that special occasions like this are not enough to insulate Audrey from the stress of their household. And to hear Audrey tell it, that's a valid fear,

"When Olivia is being a jerk and doing weird things," says Audrey, "I'll be downstairs asking for a question on my homework, and they'll say, 'Audrey, go away now,' And won't give me anything until they're done with her, which takes until, like, midnight to calm her down."

And Deb knows this isn't healthy for Audrey.

"It would be so intense with Olivia, by the time I finally got her to bed," says Deb, "Audrey would say, 'Please mommy, just come with me, lay down with me,' and by then, my whole body was just - I can't have anyone touch me. I just need to be quiet without anyone. And so there were days I'd say, 'I can't Audrey. I can't even go in there. I just need to go in my own bed and be alone.' And it breaks my heart that I even said that to her because she deserves so much more."

Psychologists like Diane Marsh of the University of Pittsburgh say the Stanas family is not unusual.

"As hard as parents may try, and they do, to meet the needs of their well siblings," says Marsh, "time and energy are simply finite. And so siblings often feel like the forgotten family members. Everyone else's problems are more important than theirs."

Marsh conducted one of the first studies of well siblings of the mentally ill and wrote about it in her book, *Troubled Journey*. Her co-author, Rex Dickens, himself the brother of three mentally-ill siblings, says that over time, sisters and brothers of the mentally ill become frozen souls.

"You sort of shut down, emotionally, in part of your life," says Dickens, "and that carries over to other areas. You can't trust, you can't feel, you can't talk. There's a core that gets frozen in time, maybe to be dealt with later, but it never does get dealt with."

Marsh and Dickens found that well siblings have higher rates of depression than the general public.

"When you have to grow up early, when you pick a fruit that's ... too green, it doesn't have a chance to mature and ripen," says Dickens. "They get kind of stopped in their development."

Other siblings worry they might "catch" what their brother or sister has. Clea Simon is a Boston journalist who wrote the memoir, *Madhouse: Growing up the Shadow of Mentally Ill Siblings*. Both of her older siblings were struck with schizophrenia when she was only 6.



Clea Simon, author of *Madhouse: Growing up the Shadow of Mentally Ill Siblings*. Photo by Karen Brown

"When you see your brother or sister grow up and change from your brother and sister to something scary and weird and alien," says Simon, "you just think that's what happens. You think that when you hit 16, you're allowed to date, and drive, and then you're hospitalized."

Simon often witnessed, or became the target of, her siblings' violent outbursts, which is why she, and many other well siblings, believe they may now suffer from post-traumatic stress disorder - a collection of debilitating symptoms from flashbacks to nightmares.

And while all families are different, most siblings seem to be affected at least by survivor's guilt. Why was my sister or brother afflicted? Why not me?

"And as they mature and they go on to careers and relationships and families," says Marsh, "over and over again we heard that it is with a sense of loss for their sibling who may not be able to move on."

As siblings age, there are practical concerns beyond the existential ones. In one clinical survey, 94 percent of well siblings reported a pervasive worry that they will have to care for a mentally ill brother or sister when their parents no longer can. And that worry is not an idle one.

Pamela Spiro Wagner and Carolyn Spiro are twin sisters - identical twins, they believe - relaxing in Pam's high-rise apartment near Hartford, Connecticut.

At 52, both are blond and petite, with long, narrow faces. But one of them looks more weathered, less groomed. You might still not know who's diagnosed with schizophrenia, until Pam starts to talk about her breakfast conversation.

"The cup, the tea cup was saying to me," recalls Pam, "'There's a chip in me and it really hurts when you drink out of that side.'"

Carolyn asks, "Did it ever occur to you that maybe the tea had an opinion too?"

"Well, it might have," says Pam.

When Pam and Carolyn were children, they both seemed fine. Like many twins, they were best friends and bitter rivals. But no one in the family, not their other two siblings nor their parents, noticed when Pam first began to hear voices. It was November 22, 1963.

While sitting in a grade-school classroom, while everyone else was riveted by the news of John F. Kennedy's assassination, Pam says she began to hear murmuring in her head.



Pamela Spiro Wagner (left) and Carolyn Spiro (right) are twin sisters. Pam began hearing voices in grade school and was later diagnosed with schizophrenia. Carolyn went on to become a psychiatrist. *Photo by Karen Brown*

"At first," says Pam, "they weren't saying anything. Then they were just saying my name and they were mangling it. 'Pam, Spam, Piro, Spiro, Piro.' And then they started saying, 'Kill, kill you, kill him, will you, kill you.' The message was a realization that I had killed Kennedy."

Pam told no one of the menacing voices filling her head. But well siblings are often the first ones to notice that something is going wrong, and Carolyn is no exception.

"She was going to school with greasy hair, greasy face, and looking disheveled and embarrassing me," says Carolyn.

They both went to Brown University, where Carolyn thrived. Carolyn didn't know it, but Pam was falling deeper into paranoia and hallucinations.

"I would just say things like, 'I feel numb, I feel like moon rock'" says Pam. "But what I wouldn't say is that there were also voices saying, 'You'll feel better if you burn yourself.'"

And then Pam tried to kill herself with an overdose of sleeping pills. She left college and moved back home.

Carolyn finished at Brown and went to medical school. Looking back, she sees she made choices very much connected to Pam's fate. She became a psychiatrist, and she married young, something she now thinks was her way of proving she was normal.

During these years Pam had lucid stretches where she honed her writing skills and won awards for poetry. But the voices always came back, and Carolyn got frequent calls from emergency rooms where Pam ended up.

"At that point," says Carolyn, "I was at my wit's end because she was becoming desperately suicidal, they were treating her like she had a terminal illness. 'You know, you might want to consider saying goodbye.'"

Pam did survive, and recently she found a medication that has kept the voices at bay. Pam and Carolyn have now told their story in a new memoir called *Divided Minds: Twin Sisters and their Journey through Schizophrenia*. They went on a book tour, trading off reading passages at colleges and book stores.

The book wasn't easy to pull off as Pam was hospitalized several times during the writing process. Even during the tour, Pam's paranoia is never entirely gone. She's still worried about something she calls the "hazmat man." That's a figure Pam sees when she looks at the hazardous materials symbol on her plastic medical baggies. Carolyn tries to empathize.

"I think I see what you're talking about, the eyebrows," says Carolyn.

"No," Pam replies, "the head is up here. The arms are over here."

Does Pam see the hazmat man as threatening?

"It's not threatening now," says Pam, "because I know where the real hazmat man is. He's locked up in an Altoid box, double duct taped."

This is where Carolyn's face goes from bemused, to exasperated.

"You don't really believe that, do you?" asks Pam. "I mean, I have the box and it's still taped up."

"Keep it taped," Pam instructs.

"I do!" says Carolyn, "but you don't really believe this, do you? I mean, in all honesty?"

Pam says, "Just keep it taped up."

"There are times when it feels like a lot," says Carolyn later. "When I am getting behind in my own bills, when she's getting sick, when she's deciding on her own not to take medication, which she's not doing at the moment, then I feel it. Then it's an imposition. Then I hate it, Yeah, you've got the freedom to not take medication because you're independent. You get to do what you want when you want to do it and the hell with whatever I want. And guess whose freedom you get to take away? Mine."

And yet, Carolyn says she can't imagine a world without the twin sister she loves, a sister who's sensitive and smart, but who clearly drew the short straw.

"I'm so lucky," Carolyn says as she cries. "When I said earlier, that I don't deserve anything, all I meant was none of us deserve anything really. We just get it, by grace of whatever. We just get it. I guess I think I could just as well be the one who got schizophrenia."

And she could have. Schizophrenia does have a genetic component. If one identical twin has the disease, the other has about a 50 percent chance of getting it, even if they've been raised separately. The rate is closer to 60 percent for bipolar disorder.

But environment is also likely to be a factor. Schizophrenia might be triggered by something as simple as a virus in people predisposed to the disease.

Regardless of the causes, one in a hundred people suffers from schizophrenia, which means that several times that number of siblings suffer along with them. To say those are the "well" ones, is, of course, a matter of semantics, because when a family copes with mental illness, no one gets out unscathed.

Credits:

Producer: **Karen Brown**

Editor: **Mary Beth Kirchner**

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Major funding for *American RadioWorks* comes from the Corporation for Public Broadcasting. Additional funding for *A Burden to be Well* is provided by The Carter Center Mental Health Program.