

MORNING STORIES TRANSCRIPT

Ah, My Brother: Author and neurologist Oliver Sacks sees the person behind the mental illness.

Tony Kahn:

Hi, everybody! This is Tony Kahn, the producer and director of Morning Stories from WGBH in Boston. Today's Morning Storyteller may be familiar to some of you. Over the years, he's been writing about people who suffer with afflictions of the brain and the mind. His name is Oliver Sacks, and he was here in Boston on a book tour for his latest collection of essays, called Musicophilia. I asked him what it was that has drawn him to the kinds of human conditions that, frankly, most of us would run away from. Here's a bit of what he said, in today's Morning Story: Ah, My Brother.

(Music)

Oliver Sacks:

Back in the 1960's, a chronic disease hospital in the Bronx, some seventy or eighty people had been unimaginably ill and often abandoned by their families for decades. Sometimes forty years, forty-five years, even. Many of them motionless and frozen in strange postures, all of whom had had the encephalitis lethargica years before. A worldwide epidemic at the time. No medicine was of any use to them.

I lived almost next door to the hospital. I was in at all hours, and in the summer, amazing things seemed to be happening. They did respond to L-dopa, and there was a jubilant, joyous atmosphere in the ward. Proposals of marriages, and people were just lyrical with delight at being able to move and talk and think again. But then, later that year, all sorts of dark clouds gathered, and complications of every sort. What had I done? I had taken them out of a - maybe a sort of passionless, but tranquil "nonbeing," and thrown them into torment and turmoil. They'd lost so many years of their life, and one of the patients said to me, "That stuff should be given its proper name: 'Hell-dopa.' "

I wanted to write about them, and in great detail, but I didn't know whether this would be proper or not. It was the patients themselves who said, "Tell our story, or it'll never be known. Give us a place, as it were, in the history of the world." I chronicle - I chronicle other peoples lives. I want to tell the story of people who might seem alien and unfamiliar and impossible to feel for. I visited a Mennonite village in northern Canada, where a fifth of the people have Tourette Syndrome. I went with a friend who himself has Tourette's and has much experience of being stigmatized and marginalized. When we got there he was on his best behavior, and at one point he sort of suddenly made a loud noise - "AH!" - and

people jumped (as you jumped just now). But then they smiled, and many of them “barked” back, and then he realized that he was at home. He was with his brothers and sisters in – with Tourette’s. This was all accepted tolerantly, generously, and with humor.

I’m rather shy in many ways. It’s a sort of malady. I was ten years old. There were times when I could hardly function, and I think I became very frightened. My brother was moving into a magical world. He started talking to himself. He felt that people were reading his mind, and listening to him. He, ah – there were strange signs and portents of every sort. I know that sometimes when I talked with him, if I spoke to him about early years, under these miles of schizophrenia, he was there. But he suffered terribly sometimes with the terror of what DeQuincey called, “The pressure on the heart of the incommunicable.”

I don’t know whether you’ve heard of Geel. It’s a village in Belgium, which since the 13th century has housed and been a home to deeply disturbed people. Mad people came from all over Europe to be cured. They weren’t cured, but the townspeople took them in and for more than 700 years, these selfless, generous, intensely human families in Geel have been taking in deeply schizophrenic people to live a life of relationship and work, of love and work. Unimaginable elsewhere! I would like to see more places like Geel.

There’s an old Jewish prayer in which you praise God for the diversity of creation. And exactly that was the feeling in Geel – that the person, the person is always there. I was deeply moved. Ah, my brother, my brother. What he went through. Such a chaotic, capricious world. But, the heart, the person is always there.

Tony Kahn:

That was Oliver Sacks with today’s Morning Story: Ah, My Brother. And I’m here in the studio with Gary Mott.

Gary Mott:

Ah. We all need a Geel. A place where people are going to accept us for who we are.

Tony Kahn:

We don’t have the village, or at least where I live, we don’t have the village. We hardly have neighbors. Just the other day, I was doing a search on Google for Morning Stories. [inaudible] What I get is a whole bunch of articles from a Tampa newspaper that has a column called “Morning Stories.” [laughs]

Gary Mott:

There you go!

Tony Kahn:

They're all about things that have gone horribly wrong in Tampa. There was one, actually, that mentioned the show. It was a woman in Colorado – Boulder, Colorado – who had just gotten into using her iPod and had come across our show. And she recommended Morning Stories as the "Podcast of the Week," to the people who read her blog. So, I just couldn't resist calling her up and saying "Hi!" and find out a little bit more about who she was.

Susan:

I really enjoy programs like yours, where – you know – it's just sharing. Regular people's stories. My daughters gave me an iPod last Christmas, and I really thought, "This was ridiculous!" Well – [laughs] I am totally hooked. You were my "Podcast of the Week" last week.

Tony Kahn:

Susan, tell me a little bit about this walking group of yours.

Susan:

I've only been living here in Boulder for twelve years. Came here knowing no one. And, it really unfortunately, or fortunately started with my getting breast cancer about a year- and- a- half after I moved here. All of my friends on the East Coast had the mentality of, "Oh my god – you have to move back here. Where are you? Out in the middle of nowhere!" My daughter discovered this fundraiser, this Avon Breast Cancer Walk, and challenged me to do that. That's how, ultimately, I got in touch with this group of women. And I decided to start blogging, just kind of summarizing the things we were talking about, the things that interested me in particular. It got much larger, and my subscriber list is growing [laughs].

Tony Kahn:

You are a connector, I get the feeling. Someone who enjoys putting people who have something in common together?

Susan:

I do. Absolutely.

Tony Kahn:

Just like my wife. She connected me, in fact, with myself. Which was quite an accomplishment! We just celebrated our twenty-fifth anniversary yesterday!

Susan:

Congratulations!

Tony Kahn:

Thank you.

Susan:

I've been married for thirty-eight years.

Tony Kahn:

Tell me what I need to know to make it to thirty-eight!

Susan:

[laughing] Oh, a lot of patience, a lot of patience!

Tony Kahn:

You learn so much by shutting up, don't you?!

Susan:

[laughing] The other thing that I have used my blog for is creating a labyrinth here in Boulder. The labyrinth was something that I also was introduced to during my treatment with breast cancer. When you walk a labyrinth path - it's a healing tool. I just got hooked. It just really spoke to me. So I started a campaign, you know, with the parks and rec department with the city of Boulder. And took eight years, but we just this past June finished construction on this beautiful labyrinth. It's maybe forty-five to fifty feet in diameter. You follow the path, one foot in front of the other, and it leads you to the center. Unlike a maze, you don't have to think about it, figure it out - it's not a puzzle. And it is a metaphor for our lives.

Tony Kahn:

You worked ten years to get this to be part of the -

Susan:

About eight years. A labyrinth-like journey. [laughs]

Tony Kahn:

Ah, ha. So what did you learn? And what were you able to teach along this path?

Susan:

Patience. [laughs] Persistence. I just had this very clear vision that this was going to happen. I didn't know if it would happen in my lifetime. It's by a creek, and was this going to interfere with the wetlands, and the flood plain, and we in fact had to get permits. We also went through many changes in personnel. I felt like we "killed off" people [Tony laughs]. But then, ultimately, there was one person at the parks and rec department that just became as committed as we were to

getting this through, and that was the turning point. He was familiar with labyrinths, and had walked labyrinths, so he knew what we were talking about.

Tony Kahn:

You never know.

Susan:

That's right. You really never know who's going to be around the next curve in the labyrinth, or who's gonna - you know - have some gem for you to grab onto.

Tony Kahn:

Well, you were just around the corner in my labyrinth today. I just want to tell you what a pleasure it was to speak to you, Susan.

Susan:

Thank you! I've enjoyed it so much.

Tony Kahn:

Okay - one last question for you, Susan. How's your health? Are you okay?

Susan:

Oh, I'm fine.

Tony Kahn:

Good. Okay.

Susan:

Just fine. I'm ten years out.

Tony Kahn:

Well! Congratulations!

Susan:

Ten years, almost to the day -

Tony Kahn:

No kidding!

Susan:

- of my diagnosis.

Tony Kahn:

Congratulations! Take care!

Susan:

Thank you, you too. Bye-bye!

Tony Kahn:

Bye.

(Music)

Tony Kahn:

Here's somebody whose illness actually kind of led her into much closer connection with the people in her community, you know. So go figure!

Gary Mott:

There you go! We'd rather not find out about mentions on your blog via Google. We want to find out directly from you.

Tony Kahn:

It's true, folks. You hear us; we really want to hear you. This is a straight, sincere request for you to get in touch with us.

Gary Mott:

and go to our website.

Tony Kahn:

In fact, we do have a video of Oliver Sacks' story, which you might want to check out as well.

Gary Mott:

And you also want to check out our Flickr page, which we've made several additions to that in recent weeks.

Tony Kahn:

And we'll be back with another Morning Story soon. Take care.

[End of Recording]