INTRODUCTION

SO THEY SAY WE HAVE SCHIZOPHRENIA

All illnesses are hard to talk about, but schizophrenia seems even harder. For many people the term schizophrenia carries a stigma so strong that just thinking about it is frightening. It reminds them of the strange thoughts, feelings, and behaviors that resulted in their needing treatment. They remember their weird beliefs and hallucinations or their disorganized, isolated, or moody ways.

Once the symptoms of schizophrenia improve, people want to put the terrifying events of their illness and treatment behind them. They want to forget. Yet, like all other serious illnesses, schizophrenia needs to be talked about. If people do not talk about their experiences with this disease, they will not learn from them and will have little control over what happens to them.

A couple of years ago, during one of our group therapy sessions, we were discussing how much had changed for us.

Figure 1.1 Group
Here’s what happened.

JOSEPH: It’s hard for me to believe now, but I really thought the FBI was after me.

AMBER: You too? I thought every time I went to the bathroom there was a camera in the ceiling where they watched me. I wouldn’t tell anyone, but I was so scared I wouldn’t go to the bathroom. I wasn’t telling them a thing.

MEREDITH: I know about that. One day I was sitting in the chair in my room. The sun was pouring in over my shoulder, shining on me. And I was sure I was the Virgin Mary. The doctor asked me, “Do you feel there is anything special about you?” I looked him straight in the eye and said, “Nope.”

JOSEPH: They would ask me questions. Did I think someone wanted to hurt me? No way I was going to tell them. I thought they were all in on the plot. You know that Dr. Mendelowitz? I thought he was the head of the Mafia.

MEREDITH: Him? Wow!

RACHEL (social worker): I remember how frightening that was for you then, but today you’re all laughing.

JOSEPH: Well, it’s funny when you think about it now. You need to be able to laugh about it.

MEREDITH: And you can’t do that with other people.

AMBER: They wouldn’t understand.

RACHEL: What about people who don’t know anyone else who has this illness? What could we do to help them be able to laugh and not feel so alone?

AMBER: You mean something like our poem?

MEREDITH: That’s an idea. We could write something.

RACHEL: How about a book? Would you be interested in doing something like that?

JOSEPH: Wow! That sounds good.

AMBER: Do you think we could do it?

RACHEL: Let me set up some meetings to see if other people might want to write a book.

That’s how this project started. And yes, we did want to write a book. We hope you won’t be afraid to share the story of our journey.

So they say we have schizophrenia. Well, when they first told most of us we didn’t believe it, or want to believe it. But it’s been a while, and now we understand it, as much as anyone can. Having been through it, we would like to share our experiences with other people for a lot of reasons.

- We don’t want people who get ill to feel so alone.
• The experience was so scary, and we think knowing what to expect might make it less scary.
• We want to change the negative stereotypes people associate with schizophrenia.
• We want to explain that the symptoms are part of the illness—they have nothing to do with the kind of person who has the illness.
• We want to show that people with schizophrenia do get better—there is hope.
• We want to show that having schizophrenia does not mean you will hurt other people.
• So many people have helped us, we wanted to do our part to help others.

This is our story. We hope it helps.

Abby        Buddy        Linda        Sam
Alexandra   Gary         Lucinda     Samantha
Alexis      Genevive     Marcus      Sasha
Amber       Ilan         Mark        Sharon
Audrey      Jackie       Meredith    Smokey
Beaux       James        Mike        Thomas
Ben         Jeff         Patrick     Van
Beth        Joseph       Richie      Vanessa
Buck        Laurie       Roman       Zelda

We have been studying the first episode of schizophrenia at our research center for the past thirteen years, and we have learned a lot. Much of what we have learned is included in this book. We could never have done this research without the help of our patients.

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INTRODUCTION

Figure 1.2 Staff

North Shore–Long Island Jewish Health System
Hillside Hospital Research Center