

Schizophrenia
FOR
DUMMIES®

**by Jerome Levine, MD, and
Irene S. Levine, PhD**



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About the Authors

Jerome Levine, MD: Jerome Levine is a board-certified psychiatrist whose research and clinical career has spanned almost 50 years. For a major portion of that time, Dr. Levine served as chief of psychopharmacology at the National Institute of Mental Health. There, he worked both nationally and internationally to help design, manage, and conduct much of the federally supported research that serves as the foundation for current approaches to the pharmacologic treatment of schizophrenia and other serious mental disorders.

After leaving the federal government, Dr. Levine joined the faculty of the University of Maryland Department of Psychiatry and the Maryland Psychiatric Research Center. Both settings treat and carry out treatment studies of hospitalized and community-based individuals diagnosed with schizophrenia. In Maryland, he also directed a program training early-career psychiatrists to become research psychiatrists.

In 1994, Dr. Levine moved to New York State, where he joined the faculty of the Department of Psychiatry of the New York University School of Medicine as a professor of psychiatry, and was appointed deputy director of the NYS Nathan S. Kline Institute for Psychiatric Research. He oversees research studying the causes, pathophysiology, and treatment of schizophrenia at basic, translational, and applied clinical levels.

Dr. Levine's residency training was at the State University of New York at Buffalo Department of Psychiatry and at St. Elizabeth's Hospital in Washington, D.C. In addition, he has served on the faculty at the U.S. Public Health Service Narcotic Hospital in Lexington, Kentucky; at the Johns Hopkins Department of Psychiatry in Baltimore, Maryland; and at the University of Pisa Department of Psychiatry in Italy.

He has published numerous papers and books in the scientific literature and is a life fellow of the prestigious American College of Neuropsychopharmacology. In addition to being listed in *Who's Who in America*, Dr. Levine was awarded the American Psychiatric Association Hofheimer Research Prize and the Distinguished Leader in Research Award from the National Alliance on Mental Illness of New York State.

Irene S. Levine, PhD: Irene Levine has a doctoral degree in clinical psychology as well as extensive experience working in the public mental health system at local, state, and national levels. She began her career as a staff psychologist and treatment team leader at Creedmoor Psychiatric Center and left to develop and direct two nonprofit psychosocial rehabilitation programs in Queens and Suffolk counties in New York.

For a period of more than 15 years, Dr. Levine held senior management roles at the National Institute of Mental Health (NIMH) and the Substance Abuse and Mental Health Services Administration (SAMHSA) in Rockville, Maryland. She was one of the architects of the NIMH Community Support Program, created and directed the NIMH Program for the Homeless Mentally Ill, and served as the first deputy director of the SAMHSA Center for Mental Health Services.

In 1994, Dr. Levine joined the Nathan S. Kline Institute for Psychiatric Research in Orangeburg, New York, where she directs communications and serves as the institute's liaison to families. She holds a faculty appointment as a professor of psychiatry at the New York University School of Medicine. She has lectured locally, nationally and internationally about the needs of families of individuals with severe mental illnesses, such as schizophrenia and major mood disorders.

For the past ten years, Dr. Levine has also been a prolific, award-winning freelance journalist and author, whose credits include some of the nation's top magazines and newspapers. She writes on mental health as well as a wide range of other health and lifestyle topics, and is currently completing a book on female friendships for Overlook Press (2009). She is a member of the American Psychological Association, the National Alliance on Mental Illness, the National Association of Science Writers, the Association of Healthcare Journalists, the American Medical Writers Association, the Authors Guild, and the American Society of Journalists and Authors.

Dedication

We dedicate this book to all the courageous individuals with serious mental illness and their families that we have met through the years, who have taught us invaluable lessons that we never learned in school. We also dedicate this book to the individuals who volunteer as research participants in the interest of helping others learn about the causes of and treatments for schizophrenia.

This book is also dedicated to our own families who have enriched our lives in ways too numerous to mention, and especially to our son, Andrew, who has been an ongoing source of pride as well as 24/7 technical computer support.

Finally, this book is dedicated to the memory of Max Schneier, one of the earliest pioneers of the family advocacy movement, who taught us about the importance of listening to the wisdom of family members.

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Introduction

Schizophrenia affects as many as 1 in 100 Americans over their lifetime and is twice as common as HIV/AIDS. Yet few other diseases are shrouded in quite as much misinformation, lack of information, and secrecy as schizophrenia is. On average, it takes more than eight years between the time symptoms first appear and the time a person is diagnosed and treated for the disorder. Pervasive stigma keeps most people in the dark until the disorder becomes up close and personal. As a result, when someone you love is diagnosed with schizophrenia — a no-fault, equal-opportunity brain disorder — you're not sure where to turn or who to tell. Initially, most people feel ashamed, bewildered, and alone.

During our careers working in various research, policy, and clinical roles at federal, state, and local levels, people with schizophrenia and their loved ones often asked us questions. We always tried to provide simple, straightforward answers, but we never have enough time to present the big picture — to answer their questions in a larger, more understandable context.

So we decided to write this book. This book distills what we've learned and read over our combined 85+ years in the field of mental health — and just as important, the valuable lessons we've been taught by patients and families during that time. In these pages, we give you immediate access to tools and information that otherwise might take you a much longer time to acquire.

We strongly believe that only through improved public awareness and enhanced mental-health literacy can society reverse the stigma and discrimination that stands in the way of finding cures and helping people with schizophrenia lead the full lives they deserve.

About This Book

Our goal in writing this book is to help demystify a long-misunderstood illness. We want this book to be your go-to primer to better understand:

- ✔ What schizophrenia is and what it is not
- ✔ What causes schizophrenia and what does not
- ✔ Why and how diagnoses are made
- ✔ How schizophrenia can be treated

- ✔ What barriers exist to treatment and care, and how you and your loved one can overcome them
- ✔ How consumers, families, friends, and professionals can work together to enhance the chances for recovery and quality of life for people with schizophrenia
- ✔ What other resources are available to help patients and their loved ones cope with the disorder

Conventions Used in This Book

We don't use many conventions in this book, but to help you access the information you need we do use the following:

- ✔ **Whenever we introduce a new technical term, we *italicize* it and then define it.**
- ✔ **Web addresses and e-mail addresses appear in monospace to help them stand out.** When this book was printed, some Web addresses may have needed to break across two lines of text. If that happened, rest assured that we haven't put in any extra characters (such as hyphens) to indicate the break. So, when using one of these Web addresses, just type in exactly what you see in this book, pretending as though the line break doesn't exist.
- ✔ **We try to avoid language that is in any way demeaning or stigmatizing to people living with schizophrenia.** In recent years, the person affected with schizophrenia has been variously called a *patient*, *consumer*, *service recipient*, or *survivor* — and the term that's preferred changes over time, and can vary from one person to the next. We tend to think of people with schizophrenia as *people*, but those in the helping professions (psychiatry, psychology, social work, nursing, rehabilitation, and so on) have a long tradition of calling the people they work with *patients*. Accepting the old adage that you can't please everyone all the time, we used the terms that flowed most comfortably for us as we wrote — although we tried to vary our language. We hope that our words don't offend or interfere with our message.
- ✔ **We try to vary the pronouns we used based on gender** — for example, not always referring to doctors as *he* and not always referring to people with schizophrenia as *she*. We didn't keep a running tally of the gender pronouns we used, but we hope you'll find it a fair balance.
- ✔ **We often refer to the person with schizophrenia as *your loved one*,** because this book is primarily geared toward people who are caring for, or closely connected to, someone with the disorder — and because we recognize that you may not be family, but your love is just as strong.

- ✔ **We generally preferred to use the term *medications* as opposed to *drugs***, because many people confuse the latter term with street drugs or drugs of abuse (like heroin, cocaine, and marijuana). That said, we do alternate use of the terms in this book — rest assured, when we use the term *drugs*, we’re referring to prescribed medications.

Also, every medication has both a *generic name* and a *trade name* (also called a *brand name*). The trade, or brand name, is the one you hear advertised on commercials (for example, Lipitor is the trade name of a medication used to treat high cholesterol, and the generic name is atorvastatin calcium). We give you both the generic and trade names when referring to medications.

What You’re Not to Read

You don’t have to read everything in this book to get the information you need. Here are some pieces of the puzzle you can safely skip:

- ✔ **Anything marked by a Technical Stuff icon:** Check out the “Icons Used in This Book” section, later in this Introduction, for more on this and other icons.
- ✔ **Sidebars:** Sidebars are boxes of gray text that appear throughout this book. You’ll find interesting information in sidebars, but nothing essential to understanding the topic at hand.
- ✔ **The copyright page:** If you like reading fine print, have at it. Otherwise, trust us: You don’t need to know what’s there.

Foolish Assumptions

In writing this book, we assumed the following about you:

- ✔ You may be caring for someone who has symptoms associated with schizophrenia or has been diagnosed with schizophrenia.
- ✔ You may be a parent, family member, friend, or colleague of someone who has schizophrenia, and you want to understand more about the disorder and what you can do to help.
- ✔ You may be a mental-health or medical professional reading the book so that you can recommend it to loved ones seeking more information about schizophrenia.

Although we haven’t written this book specifically for the person with schizophrenia, if you have schizophrenia and want more information on the disorder, you’ll find this book useful as well.

How This Book Is Organized

We've divided this book into five parts. Here's what you'll find in each.

Part I: Understanding Schizophrenia

In this part, we give you a broad overview of schizophrenia, separating what's real from the myths and misperceptions. We describe the symptoms and unusual (and sometime disturbing) behaviors commonly associated with the disorder and explain how clinicians distinguish the symptoms of schizophrenia from those of other serious mental disorders. We describe the onset of the disorder, which can come on suddenly, seemingly out of the blue, or may make its appearance so gradually that it's barely noticed.

Part II: Finding Out What's Wrong and Getting Help

Getting a diagnosis is the first step in getting help. In this part, we explain how the diagnosis of schizophrenia is made and identify the different types of schizophrenia. We also give you tips on how to assemble a healthcare team for diagnosis and treatment, and what to do if things don't seem to be functioning as smoothly as you would hope them to. Finally, we provide advice on starting treatment, including navigating the financial hurdles you'll likely face in paying for care and dealing with your loved one's potential lack of insight into the illness.

Part III: Treating Schizophrenia

Antipsychotic medications are the cornerstone of treatment for schizophrenia. This part explains how psychiatrists select a first medication, and how and why they make adjustments. We also provide advice about how your loved one can cope with common side effects and offer tips for encouraging your loved one to stick to her medication schedule. We explain the range of treatments for schizophrenia and fill you in on what's known and unknown about complementary and alternative treatments. Finally, we identify new and promising directions in research and explain the benefits and risks of participating in clinical trials.

Part IV: Living with Schizophrenia

Schizophrenia presents challenges not only to the individual with the illness, but also to the people around them. Families need to stay positive and optimistic, and avoid blaming each other for the illness. In this part, we tell you how families can avoid burnout, work collaboratively with professionals, and acquire the coping skills they need in order to handle their loved one's not-so-pleasant behaviors. This part also provides suggestions for finding decent affordable housing and for learning how to handle psychiatric crises to minimize their adverse impact. Finally, we define and explain the importance of recovery and meeting the needs of the whole person, which transcend treatment alone.

Part V: The Part of Tens

Every book in the *For Dummies* series includes a part called The Part of Tens, which offers helpful hints to empower readers. In *Schizophrenia For Dummies*, we debunk ten myths about mental illness, offer up ten tips for coping with your loved one's disorder, and ten ways your loved one can avoid relapse.

Icons Used in This Book

Throughout the book, we use icons — little pictures in the margin — to highlight certain kinds of information. Here's what the icons mean:



When we use the Remember icon, it means that we're highlighting essential information that's worth remembering.



Schizophrenia, like many other illnesses and disorders, is complex. When we get into the details that you don't absolutely need to understand, we mark it with a Technical Stuff icon. You can safely skip these paragraphs without missing the point — or you can read them and find even more information.



The Tip icon highlights advice or pointers to help you cope with the symptoms and behavior associated with schizophrenia and to deal with the complexities of treatment. We've worked in mental health for years — think of these paragraphs as our insider tips on dealing with schizophrenia.



The Warning icon signals potential risks and dangers. You won't see it used often, but when you do see it, be sure to heed the warning.

Where to Go from Here

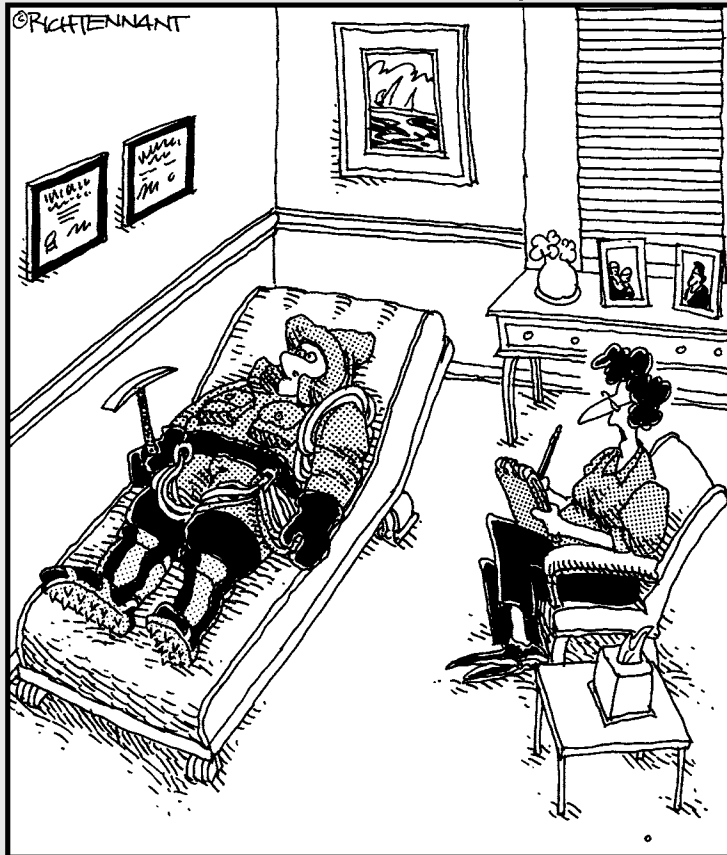
If you're the kind of person who reads the morning newspaper from front to back, you'll probably want to start with Chapter 1 of this book and read straight through to the index — in fact, you've probably already read the title page, copyright information, table of contents, and everything else that comes before this Introduction. However, you don't need to read this book in sequence to get a lot out of it. If you're coping with a particular issue or problem, use the table of contents and the index to guide you to the specific portion of the book that addresses your questions. For example, if you think your loved one may have schizophrenia, but he hasn't yet been diagnosed, turn to Chapter 3. If you're looking for doctors for your loved one, Chapter 5 is the place to start. If you're looking for a place for your loved one to live, Chapter 13 has the information you need. Use this book in whatever way works best for you.

Part I

Understanding Schizophrenia

The 5th Wave

By Rich Tennant



"My hunch, Mr. Pesko, is that you're still making mountains out of molehills."

In this part . . .

We kick things off by giving you an overview of schizophrenia — a no-fault, equal-opportunity disease of the brain that strikes teenagers and young adults in the prime of their lives. Here we dispel some of the myths and misunderstandings associated with the disorder, which have led to unnecessary blame and social stigma. We also show you how to recognize the early warning signs of the disease, outline its risk factors, and cover the range of symptoms and behaviors that characterize schizophrenia. Finally, we tell you how doctors are able to differentiate schizophrenia from other mental disorders with seemingly overlapping symptoms, and discuss the fact that — although treatments have vastly improved the lives of people with schizophrenia and their families — much more remains to be learned.

Chapter 1

Understanding Schizophrenia: The Big Picture

In This Chapter

- ▶ Understanding what schizophrenia is, who gets it, and what the symptoms are
 - ▶ Looking at how schizophrenia is treated
 - ▶ Getting the support you need
-

Schizophrenia. If someone you know has been recently diagnosed with schizophrenia, the very word may evoke a cascade of intense feelings: sadness, fear, confusion, shame, and hopelessness. You may ask yourself, how did this happen? Why did it happen to my loved one? It's natural to have these emotions. But take a deep breath. You need to know that the diagnosis isn't as catastrophic as it first appears to be.

Most people know very little about schizophrenia until it hits home, and what they do know is likely to be based on old myths and misperceptions. They need to find out as much accurate information as they can about this complex and misunderstood disease. Knowledge is power — and knowing what schizophrenia is (and isn't) is the first step toward moving beyond your worst fears.

In this chapter, we give you an overview of the brain disorder known as schizophrenia: what it is, who gets it, and what treatments are available. We dispel some common myths about the disorder and tell you how schizophrenia differs from other mental illnesses. Finally, we tell you the good news about the disorder and why you and your loved one have every reason to remain hopeful that recovery is possible.

Schizophrenia is a serious, long-term, life-altering illness, so it's natural to be stunned upon hearing the diagnosis. You may even feel paralyzed, not knowing what to do next. But the first step is clear: You need to gather all the information you can to make sure your loved one is getting the best possible treatment and supports available to him.

Defining Schizophrenia

You're reading this book, which means you probably have a personal interest in schizophrenia — either you or someone close to you has been diagnosed with the disease or you're worried about someone showing signs or symptoms. In this section, we fill you in on what's currently known about schizophrenia and the way the disorder affects the people who have it, as well as their loved ones.

What schizophrenia is

Schizophrenia is a brain disorder characterized by a variety of different symptoms, many of which can dramatically affect an individual's way of thinking and ability to function. Most scientists think that the disorder is due to one or more problems in the development of the brain that results in neurochemical imbalances, although no one fully understands why schizophrenia develops.

People with schizophrenia have trouble distinguishing what's real from what's not. They are not able to fully control their emotions or think logically, and they usually have trouble relating to other people. They often suffer from hallucinations; much of their bizarre behavior is usually due to individuals acting in response to something they *think* is real but is only in their minds.

Unfortunately, because of the way schizophrenia has been inaccurately portrayed in the media over many decades, the illness is one of the most feared and misunderstood of all the physical and mental disorders.

Schizophrenia is a long-term relapsing disorder because it has symptoms that wax and wane, worsen and get better, over time. Similar to many physical illnesses (such as diabetes, asthma, and arthritis), schizophrenia is highly treatable — although it isn't yet considered curable.

But the long-term outcomes of schizophrenia aren't as grim as was once believed. Although the disorder can have a course that results in long-term disability, one in five persons recovers completely. Some people have only one psychotic episode, others have repeated episodes with normal periods of functioning in between, and others have continuing problems from which they never fully recover.

Who gets schizophrenia

No group is risk-free when it comes to schizophrenia, but some people are more likely than others to develop the disorder. The following statistics may surprise you: