

The Left Atrium

The stigma of silence

Nothing to hide: mental illness in the family

Interviews by Jean J. Beard and Peggy Gillespie

Photographs by Gigi Kaeser

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Ignorance, silence, fear, disbelief, misunderstanding and blame are common reactions to people with mental illness. In the foreword to *Nothing to Hide*, Kay Jamison writes that stigma against mental illness is ancient, prevalent in all societies, and continues to adversely influence public and political responses. Jamison speaks with authority, not only as a professor of psychiatry at John's Hopkins School of Medicine, but also as someone with bipolar disorder who remained formidably ill and untreated for many years. As she confides,

I first became ill with a severe form of manic-depressive illness when I was a senior in high school. Like many people who get psychiatric disorders, I had absolutely no idea what was happening to me. ... I finally received medical care — more than ten years after my first breakdown.

One of the ironies of mental illness is that by ignoring painful symptoms patients may stigmatize themselves further. Family members also suffer as a result. In the introduction to *Nothing to Hide*, Kenneth Duckworth, also a psychiatrist, tells of a shattering experience in grade two when his father suffered a manic breakdown:

I assumed that my situation was unique, that no one else was experiencing the anxiety and fear that accompany a big and poorly understood condition like bipolar illness. Had I been able to imagine that millions of American kids were dealing with a variation on this theme, I would have felt less alone.

Duckworth's account, like Jamison's, underscores a tragically common circumstance: people with mental illness

often have symptoms for many years before they seek help. Bewildered and unsettled, they struggle in a society that neither empathizes with nor understands their predicament.

This book takes the reader on a journey to unstable regions of the psyche: anxiety, depression, panic, schizophrenia, eating disorders, mania, suicide, obsessive compulsion and substance abuse. In describing common psychiatric disorders and their treatment, Duckworth dispels some of the myths perpetuated in the media — for example, that psychiatric patients are violent. (Statistically, they are not.) Mental illness is, unfortunately, quite common. The US National Institute of Mental Health estimates that 22.1% of Americans aged 18 and older — about 1 in 5 adults — suffer from a diagnosable mental disorder. Using the 1998 US census, Duckworth translates this figure to 44.3 million Americans. Assuming a similar prevalence in this country, over 4 million Canadians have a mental illness.

Who has not had to share the pain of a family member, classmate, colleague, friend or lover struggling with mental illness? As if coping with the symptoms of the illness were not bad enough, there is, as Beard and Gillespie argue, "an additional challenge: the pervasive and destructive burden of stigma. Stigma gives rise to myths, stereotypes, and misunderstandings." Beard and Gillespie travelled across

America to interview families affected by mental illness, later presented the results of their project as a touring exhibit, and have now published this book to reach a broader audience.

This book includes interviews with 44 patients and their family members, accompanied by black-and-white photographs by Gigi Kaeser. What emerges is an album of mental illness from a first-person perspective. Although there have been excellent popular books in recent years on mental illness, such as Kay Jamison's *An Unquiet Mind*, Andrew Solomon's *Noonday Demon*, William Styron's *Darkness Visible* and Mark Vonnegut's *The Eden Express*, the narratives in *Nothing to Hide* illuminate a dark collective wisdom. Here is a sampling of voices.

Trinidad Azusa tells us,

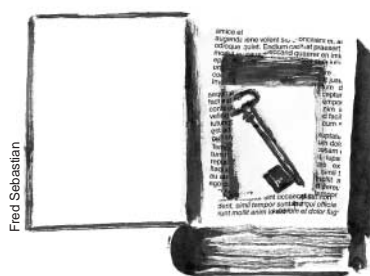
I was working as a tax auditor when ... symptoms of my illness suddenly appeared without warning ... [P]eople were always watching me. I would walk by the TV set and think the voices of the actors were talking directly to me ... [A]t work

things got very difficult ...

[M]y dad and my older brother took me to the hospital ... I was initially diagnosed with schizophrenia ... I was in denial at first ... [E]ven though I knew something was seriously wrong with me, I didn't want to believe I was mentally ill.

Jodi Campbell writes of her sister's schizophrenia:

When my sister Jamie first became ill, I was in my last year of middle school. I was scared all the time ... I never knew what was going on ... None of us in the family knew what was wrong. At first I tried to isolate myself from my sister ... I struggled with every single emotion you can think of ... [O]ne day I walked into the kitchen and found Jamie lying on the floor ... I'd get scared because I didn't think I could let her out of my sight.



Fred Sebastian

Paul Gottlieb, a successful publishing executive struggling with a mood disorder writes:

Where I worked, if you had a heart problem or cancer, you'd never find a more sympathetic, supportive group of people ... but for years I had to be secretive about my mental illness because I was in control of millions of dollars of the corporation's assets, and I couldn't run the risk of having my judgment mistrusted.

Fred Frese says,

I was diagnosed with paranoid schizophrenia when I was only twenty-five ... [F]or the next ten years I was in and out of various mental hospitals ... Today I am the Director of Psychology at Western Reserve Psychiatric Hospital ... [T]he thing is, people do recover.

Molly Cisco says,

I can remember lying in a snowdrift ... when I was six, looking up to the stars, and wishing that my life would stop, that everything would stop.

The patients who tell their stories in this book are old, young, urban, rural, and from various cultures and socioeconomic strata. Many feel anger toward medical or legal systems for failing to understand and help; others feel rage and despair at the postmorbidity changes in their sense of self. There are stories of hope, of the persistence of severe mental disorders, and of suicide. As a psychiatrist I was deeply moved and informed by the candour of these narratives. The direct power of each voice to convey the raw material of life, the truth of mental illness, is penetrating and profound. The reader follows each narrative, peers into the photos, and senses anguish. This text is essential reading for medical professionals and the public.

Ronald Ruskin

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Room for a view

Between five and six

The hospital is a huge beast that eats but does not sleep. Its silent nighttime chambers lie heavily, pressing all around. Slowly breathing. The indrawn swell of air, the exhalation of steam from grated vents, is a tide that slows at night. The weight of the beast settles more heavily in these hours; there are fewer souls to hold it up. The hour between five and six am is when the hospital comes closest to a sleep state. But it does not sleep.

Neither do you.

Somewhere there is a bed, a narrow and lumpy mattress that leans dangerously and has a plastic covering that keeps the sheets damp with sweat. There is no sleep there, only tossing and turning until your pager goes off. The labour of dragging yourself upright is worse between five and six than if you had never lain down. Better to float along the quiet and mellowly lit hallways, alone. Better to shy from the fluorescent light.

Fluorescent light is an assault between five and six. Those who work in it are angrily awake. It scours the eyes, throwing ugly, dark, half moons under them. It yellows skin and glistens in the thin grease at the hairline. Every unsavoury detail of being awake so late is heightened under fluorescent light. Feet in wool socks and sandals smell sharp; socks stiffen at the heels. The cheap, ropy collar of your surgical scrubs scratches at an oily pimple forming on the back of your neck. The rough top shifts across the dry itchy skin between your shoulder blades, giving off a rich whiff of armpit. Your teeth feel dull and mossy under white fluorescent light; you try to drown bad breath with black coffee. You stay, whenever possible, out of fluorescent light. You favour instead an old lounge with stale ashtrays. You look out the window, across the emergency department parking lot.

The winter air outside is becoming lit from within, turning from black into blue. Huge stars of frost expand on the silent car windshields. Steam rising from the vents outside thins to ribbons,

dissolves into the clean air. This hour is yours alone. At this hour, the pager is eerily dormant. Window glass is cold against your forehead; your eyes are red and dry. You breathe the cool air close to the pane. Snow and ice make everything look so

clean outside in the parking lot, even the frozen vomit, pink with yellow corn. The hospital will begin to shift and stir soon enough, but for now its thoughts wander.

Perhaps it, too, looks outward, at the world. In this quiet moment, you watch another day being birthed between the cars in the parking lot.

Somewhere, deep inside one of the seven stomachs of the beast, an anesthesiology resident sits, wearing scrubs, on the lid of a toilet. Snaking out from each arm is a clear plastic tube. The bathroom door is locked. He turns and places his wire-rimmed spectacles on top of the toilet tank. He won't need them where he is going. The beast holds its breath. The anesthesiology resident closes his eyes for a moment. At last he leans forward, perhaps with a small, relieved smile. He leans forward, and opens up each of the IV lines wide. First the left, then the right. Fluid and medicines flow into his veins, and he leans back against the tank, losing a papery sigh. He has been trained exactly how to do this; to first anesthetize, then paralyze; to numb, then cut.

Now the quiet beast stirs. The hallways seem to widen a bit. The pressure



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