



# **Dancing at the River's Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness**

*Alida Brill , Michael Lockshin*

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An invaluable resource for medical professionals, victims of chronic illnesses, and their loved ones, this dual memoir by a doctor and his longtime patient traces the growth of their unique friendship over a span of decades. By exploring the bond between caregiver and sufferer, this sensitive account evokes not only the constant day to day frustrations and emotional toll suffered by the chronically ill, but also an understanding of the mental struggles and conflicts that a conscientious doctor must face in deciding how best to treat a patient without compromising personal freedoms. In alternating chapters, the narrative explores the frustration, joy, despair, grief, and pain on both sides of the doctor-patient relationship.

## Dancing at the River's Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness Details

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# **From Reader Review *Dancing at the River's Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness* for online ebook**

## **Jeff Wong says**

I found this a very interested read. The format is set up in partially alternating chapters between the patient (Ms. Brill) and her Doctor that formulate their perceptions of her chronic intermittently relapsing severe medical condition. I would highly recommend this for anyone but especially for teachers of physicians-in-training/medical students (and the trainees themselves) for gaining an important patient-centered perspective on chronic illness and how physicians can (sometimes) help but frequently impede the therapeutic process.

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## **Dawn says**

If only all doctors were like this. Both authors bring great insight into the patient/doctor relationship that exists in chronic illness. Alida shows what it's like not just to live with chronic disease (luckily for her, able to have a successful professional life), but all of the loss that comes with it--relationships, friends, family--how many people walk away because they don't understand and it becomes too much to deal with; she does an incredible job of explaining the struggles almost all of those living with chronic illness face--bad doctors, missed diagnoses, self blame, living with a body that's revolting. Dr. Lockshin does an excellent job explaining what it's like to be on the medical side of the fence--taking care of patients who will never be cured, helping them navigate their treatment, learning every step of the way, but never actually knowing what it's like to be one of them.

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## **Starlia says**

I reallly, realllly, realllllly want to read this book

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## **Christine says**

This was a wonderfully written and thoughtful account of a doctor and a patient and their mutual struggles.

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## **Barbara (The Bibliophage) says**

Patient Alida Brill and her physician Michael Lockshin, MD collaborated on the creation of this book. It's divided into sections written by each of them, with more from Alida than Dr. Lockshin.

Alida Brill has lived with chronic illness since her teens. And in her career she's fought for women's rights and for women's issues. She has lived a full and rewarding life, despite the incredible daily challenge of her illness. I highlighted countless passages from Alida as I read. She is eloquent and tremendously insightful about the world of chronic illness.

Her connection of the desire for love and support with feminism and the male ego is nothing short of brilliant. She writes, "Chronic illness in a female partner gnaws at a man's sense of control, his sense of power, his sense of being victorious against danger. Call it what you will, and if you wish, go ahead and accuse me of being politically incorrect. Whatever you want to label my remarks, it remains the case that a chronically ill woman threatens a man's sense of himself, and calls into question his feelings of success as a man, a lover, a "white knight.""

I also appreciated Alida's section on the tendency of patients with chronic illnesses to blame themselves for their illness. And why we shouldn't!

The sections from Dr. Lockshin didn't connect as strongly for me, perhaps because I'm a patient rather than physician. I found him to be caring and knowledgeable, but certainly not transcendent like Alida. Essentially, he's cultured and curmudgeonly older man with genuinely sincere intentions.

Here's an example: "Powerful thing this, the training and license that grant me the ability to destroy or sustain another's dream. Sobering and frightening and nauseating thing this, the knowledge that I sometimes actually do exercise this power. Humbling thing this, to be able to use this power, once in a while, to salvage lethal mistakes, made seriatim, on a cheeky Puerto Rican kid with a tattoo."

I've read many books about living with chronic illness. I'm sure this will remain one of my favorites for a long time!

Thanks to NetGalley, Schaffner Press, and the authors for the opportunity to read a free digital copy in exchange for an honest review.

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## **Jennifer (JC-S) says**

‘Visiting and inhabiting the world of chronic illness are two very different things.’

This book has a particular resonance for me: my autoimmune disease is causing eye related problems and I am currently legally blind in my left eye. From 6/6 to 6/60 in three months is a big jump. And so, I have a particular interest in chronic illness especially those with an autoimmune component.

I read this book during a day, have dipped into and out of it since and will continue to do so. I am simultaneously enlightened, inspired and saddened.

We are all touched by chronic illness, each in our different ways. Some of us feel it, some of us observe it, some of us care for people fighting with or suffering from it, many of us know or work alongside sufferers, while others try to provide answers.

And sometimes, one person can fill a number of these roles.

Chronic illness is an umbrella label for a number of different diseases and disorders that turn our individual bodies and minds into enemies rather than friends. Sometimes, the signs are obvious but often they are not. Chronic illness is often compartmentalized into neat medical chunks which may make treatment ‘easier’ for medical practitioners but often does little for patients who see themselves as progressively depersonalised through this segmentation.

I applaud Ms Brill and Dr Lockshin for sharing their experiences with readers. Medicine cannot provide all of the answers and may not, yet, have identified all of the questions. Doctors and patients dance an intricate

pavane but often with differing steps because of different senses of time. I think the hardest thing about chronic illness is knowing, and then accepting, that containment rather than the cure is the most likely positive outcome at the individual level in real time.

In bringing their shared experiences and unique perspectives together in this book, Ms Brill and Dr Lockshin invite us to read, absorb and reflect. I thank them for taking the risk of inviting strangers into their thoughts and experiences.

This book does not contain easy answers but it does enable you to see some of the milestones on the journey and, perhaps, to read time better than I can. I would recommend this book unreservedly to those of us living with chronic illness, and for all of those involved in caring for or about people. I think that includes most of us.

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### **Tom says**

I ordered this book to see if it was useful to include in a course on the theoretical foundations of family medical practice. It is a dialogue between a very articulate and accomplished individual with a chronic disease (Wegener's granulomatosis) and her physician. There are a lot of useful insights for medical practitioners. The book or, at least some of the chapters, should be useful for stimulating discussions.

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### **Gen says**

Would love to read. Dealing with lupus everyday. Love to read this!! Will read this!!

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### **Veronica says**

I prefer to not think of myself as someone with chronic disease. Since at least age 7 I've been on some sort of allergy pill for hayfever. Sneezine, runny nose, itchy eyes & occasional bloody noses were just life not a disease. But after having gestational diabetes and watching my mother die so young, I began reflecting on her own journey of chronic disease. I was barely in high school when she was diagnosed with rheumatoid arthritis - me about 13, her 31. I'm older than that already...and I can feel it. I've forced myself to think of people with chronic disease as someone other than me out of fear. Fear that I won't be able to live my life the way I want.

And that's just where *Dancing at the River's Edge* fits into my life, perhaps into yours. Alida has lived a full life, not the life one aspires to with her many trips to the hospital, but a life rich enough to be proud of. At the same time, *Dancing* also gives us a peek into our doctor's head. Alida's long-time doctor, Dr. Lockshin, takes his turn in telling his side of the story - both as Alida's provider, but also as a doctor who knows that most of his patients will never recover or get well. Kids don't grow up wishing to be doctors of people they can't cure.

In the end, *Dancing* is a book of hope. Hope that despite the pills, the IVs, the hours spent on that damn paper-lined table that we will still have full and rich lives. That we are still owed love and respect. That our doctors are struggling with us as well. This fact may scare some, but I am actually comforted by this tidbit. It flattens the playing field. It makes me think that perhaps some of us are partners in healing, not just receivers

of wisdom in the form of a pill.

\*\*excerpted from my full review on my blog.

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