I wrote a book when I was 17 years old about traveling on the trains of Europe alone. I was a publishing major at Emerson College in Boston, a student at one of the country’s top schools for communication. I thought I’d be a successful writer. Instead, the day after graduation, I found myself in a hospital bed, unable to communicate rationally with anyone.

That was a decade and a half ago. Since then I’ve been hospitalized about nine times, one Christmas and a New Year’s, my dad’s birthday, and Valentine’s Day. But none of these hospital stays have been quite like that May morning my parents first took me to McLean Hospital in Belmont, Massachusetts.

It was the day after my graduation ceremony, when I bolted out of the row with the other graduates. I was still wearing my cap and gown, but I never made it to the stage to accept my diploma. They found me wandering in the lobby of Emerson College’s Majestic Theater while Ted Turner was still giving the commencement address.

I realized much later I was clinically “psychotic” that day. Learning that I suffered from schizophrenia has made me do many things differently from what I’d planned, often still different from what I’d like to do.

Instead of being the successful high-powered professional I’d envisioned, I simply wrote a book about my experience. Much to my surprise, it led to a career as a public presenter concerning mental health.

During the past three years I have spoken at libraries, colleges, university and public forums, sharing my story and views of successful responses to mental illness. I’ve also coached others, offering methods to confront the problems their illness creates.

Our pasts can be rewritten to provide perspective to our present. And if we are successful, our future can have a new and extraordinary dimension.

Often in therapy, psychiatrists and patients talk about the past that has hurt us. Sometimes there can be no reason for the painful things that happened, but we can learn from them. We can also go one-step further- beyond any rational “analysis” and rewrite our life story.

The past is not the just past, but an integral part of our present. And our present must not be only our present misfortune. We can develop new themes in our lives that defy our hardships and create context for what is to come. These themes may return years later with new twists of triumph or tragedy. They are our themes, and belong to us. Meanwhile, we can celebrate our present and future by creating a healthy now.

Fourteen years later, after that day in May of 2000, when I was unable to make it to the stage to accept my diploma I had a chance to return to Emerson. A group of Emerson
students invited me after attending my keynote address at a Symposium at Wellesley College dealing with mental health on college campuses. When I returned to speak at Emerson, my father was dying of cancer. It would be the last time he ever heard me give a public presentation. Both my parents were there. They had also been at my aborted graduation, so we never shared that experience of my receiving a diploma. The talk went wonderfully. Afterwards, the provost of Emerson surprised me by officially presenting me with the Emerson diploma I had missed getting handed to me during that day in May, nearly a decade and a half ago.

I was stunned that the President of Emerson had personally asked the provost to be there, because he was out of town. My parents were able to finally share this moment with me in the context of having rewritten my story.

Loss is much more than a single event. In mental illness there is often a break when life as we have known it, a life within our minds, a life with others, is irrevocably altered. The onset of illness may also be the beginning of many lost moments and memories. Healthy people can understand loss by losing loved ones or with time they see passing. But in mental illness there is a feeling off loss every day, often every hour of the day. But psychiatrists and those of us with mental illness sometimes focus too much on losses, and not the landscape of our lives- with its past, present and future.

Patients must not be seen as only what is before them now, they should be perceived as individuals who are a continuation of their pasts, and given a reason for a hopeful future, no matter how dire the diagnosis.

When I was first admitted to Mclean Hospital this didn’t happen. Despite graduating the day before, and having toiled for four years to earn my degree, I instantly became reduced to “psychiatric patient.” I emerged a month later knowing nothing but my new-confused mind. My past passed just as the person I had known as “me,” had been transformed into a figment of what I had known myself to be. No effort was made to help me reconstruct my life story in its new context. All I had as a framework was my illness. Others with mental illness have had similar experiences. Many patients rage at being treated as a diagnosis with its entire stigma, rather than as individuals.

Consequently, they lose a sense of purpose, a sense of self-worth. It is a loss to the relation between the energy life gives and the energy we give it. There is little dynamic to our surroundings, and us ourselves in relation to others. We are caught in disorientation to our environment.

Sometimes the world is a rude awaking. Its raw sorrow confronts us as we open our eyes in the ward, and it seems like there is no going forward in a reality that demands action. Sleep is a welcome relief, our bed a refuge to all our problems. After my first hospitalization for schizophrenia I would awake and hear voices, whispers that may or may not have been real. I later heard whispers of those in my house. I thought they
whispered not to disturb me, as though I were a fearful king of madness. I felt special but in a bad way, a lonely exception, something to avoid.

Mental illness may be a break from the bonds we shared with those we loved, and who loved us. Some remember how inappropriately we may have acted, and are afraid we will act that way again. This creates a separate mind, one that upon waking we confront in all its reality. We must exist in a world that is alienating. There are philosophical reasons, there are psychiatric reasons, but the crucial issue is how we are able to function, even get out of bed and continue on every day.

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After my diagnosis I cried for months when I woke up in the morning. I felt shame and could hardly face another person, meekly passing by others to sneak a cup of coffee and return to my room. The feeling subsided as the morning passed, and soon I could confront the day. I realized not getting out of bed would be even worse. I realized I must survive. I knew I would stay that way if I fell prey to the illness.

The answer to helping patients is to expose them to life, not isolate them with their illness. We need to bring a relief to this struggle with a purpose for living; just surviving without a purpose is madness. This is necessary for life to be a sane struggle, not an insane quest toward accomplishment.

The meaning of life, not the madness of society’s stigma, must be the approach to the patient. This can be cultivated into a positive psychology that includes the struggle of all, to find purpose within terrible feelings of need.

Despair is an opportunity the mentally healthy often lack. Realizing we are experiencing the essence of life’s condition --is an empowerment like no other. This is living on the pulse of life.

Once we realize we are living the human condition, time opens up. We have the time to empower our goals and ourselves. Recovery follows and we can blossom into a beautiful power. No longer are we merely a manifestation of a devastating disease.

I’ve decided to go out and find a perspective outside the shame and sadness I have felt for having schizophrenia. This has been an awakening for me, a decade and a half after my diagnosis.

During the day after my first admission into McLean Hospital in May of 2000, I gradually realized I was in the center of a room in a hospital bed. I could hear the crinkle of a plastic mattress, and my pillow felt strange, sanitary, but in a dirty way, as if I were the one who would make it dirty. I saw a face through a square piece of glass on the door every 15 minutes. I could hear a murmur of voices outside, and I went in and out of sleep.

One of the first things I noticed upon waking was a jade plant my parents bought for me. It looked like a million get well cards and flowers, but it had just a green color. I finally felt safe and cared for, and put my trust that something would be done to help me.

I moved into a halfway house a month after my college graduation, and became exposed
to very different people I never would have known. People were very sick all around me. In lucid moments, some told me stories. I listened, and tried to draw from my compassion. I still had my own hate and horrors to live through.

Now I have my own stories to tell, presenting around the country to universities, libraries, and various mental health organizations on topics ranging from quality of care issues to family dynamics; and sharing my story has broadened my perspective, and hopefully offered insight to others. I think about the identities given to those who need help. There is often the belief that the poor and disabled don’t contribute, that they are not the ones who lead society to progress. But, their experience of tragedy in life, and the struggle for love and belonging, is an archetype, part of the story we all share. This is a sane story, one that should not be excluded.

I cannot ignore my struggle, because it is in my mind everyday as mental illness, but I can focus on what happens inside, away from my sometimes-clouded mind. I can be a part of society, and contribute to it by living a dedicated life, even when society’s progress is off course.

During years of speaking, I have heard people’s stories that made me realize the universality of the human experience. We all face adversity in different ways. Pain should not be ignored in a public display of privilege. Our hardships should be shared. This is the only way to make sense of the human struggle, and give meaning to it in mental health.

Ben Boone can be contacted for public speaking requests at minorityofmind@gmail.com
COULDN’T MAKE SENSE OF EXPERIENCES DIDN’T KNOW WHAT MENTAL ILLNESS WAS AND DIDN’T KNOW I WAS GETTING IT.

FIRST EXPERIENCES OF MENTAL ILLNESS IN SCHOOL

COMPUTER LAB
ERIC
EMERGING SYMPTOMS IN SCHOOL

CREUISE SHIP
BEGINNING OF SYMPTOMS DETAIL
EMPHASIZE HORROR
HELPING OTHERS CHEF’S ONE DAY
MINORITY OF MIND VERY SICK STILL

ACTION OUTSIDE MY MIND
RECOVERY BEGINS EXPERIMENTS IN IMAGINATION
TURNED TO NATURE AND CREATIVE SOLUTIONS

CREATED WHAT I CALL CLOUD THERAPY

END