

# Living with Mental Health Challenges: Personal Stories of Recovery from Across the Globe

A Conversation Guide for Family Members and Friends\*

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You can download the stories we reference in this study guide for free. Please see the "Living with Mental Health Challenges" volume of VOICES here: <a href="https://nibjournal.org/voices/">https://nibjournal.org/voices/</a>.

The sociologist Art Frank wrote a short article on learning from narratives for NIB. Please visit <a href="https://nibjournal.org/education/narratives/">https://nibjournal.org/education/narratives/</a> or see the Narratives Page under the Education tab on the NIB website to download Art Frank's article.

# **General Questions:**

- 1. Many of the authors talk about how it can be difficult to address stigma and bias about mental health challenges. What stereotypes do the authors discuss in the stories? As a family member or friend of someone living with mental health challenges, how do you fight bias or push back against negative stereotypes? How, if at all, have your ideas or beliefs about "mental health challenges" changed after reading the stories?
- 2. What are some of the different meanings of recovery that the authors discuss in the stories? What does "recovery" mean to you? In your opinion, is "recovery" possible?
- 3. The Western biomedical model of psychiatry focuses on using medications or drugs that affect the mind, emotions, and behaviors to treat mental health challenges, but social or financial stressors can also cause mental health challenges. What are some of the strengths and weaknesses of using only medications to treat mental health challenges? What strategies could address the social or financial problems that can also affect mental health? What are the barriers to using these strategies?
- 4. What are some of the biggest challenges of supporting family members or friends with mental health challenges? How do you face these challenges? What are some of the rewarding or beneficial aspects?

<sup>\*</sup>Created to accompany VOICES: Stories from the Pages of NIB, 2021, which contains the narrative symposium from Narrative Inquiry in Bioethics, Volume 11, Issue 2, titled, "Living with Mental Health Challenges: Personal Stories of Recovery from Across the Globe."

# **Story Questions:**

# My Wedding Day

Syrena Oswald, Canada

- 1. Syrena remembers a severe manic episode that led to her hospitalization and diagnosis of Bipolar I. Was there a distinct episode that led to diagnosis for your friend or family member? What is your recollection of that episode?
- 2. Syrena shares her story to bring light to mental healthcare practices that might need to change. In your opinion, what are some common practices in mental healthcare that need to change? What would need to be done for those practices to change? What could get in the way of it changing?

#### From Fear to Love

Glenn Roil, Canada

- 1. Although Glenn had other family members with mental illness, this was "swept under the rug and not spoken about." Glenn he was made to feel like the "black sheep in the family and the only person who struggled." Was mental health discussed openly in your family? Why or why not?
- 2. Glenn writes, "What has been challenging for me was dealing with my family, who did not understand or accept me or other people facing mental health challenges. My immediate family did not support me when I needed them the most." As a friend or family member of someone living with mental health challenges, how do you best support them? Even though you might not understand their experience, how do you show love and acceptance?

# A Voice of Hope for Mental Health in Cambodia

Bunna Phoeun & Fr Kevin Conroy, Cambodia

- 1. Although Bunna had experienced "many problems" related to her behaviors, she did not know that her behavior was a sign of mental illness. When you noticed troubling signs in a friend or family member, how did you encourage them to seek help? Did they listen to your advice? If not, what finally prompted them to seek help?
- 2. Bunna was hesitant to share her mental health struggles with co-workers because she worried that they would think she was a "psychopath." How did you find out about your family member or friend's mental health challenges? Did they tell you? Why might it be hard for them to talk about their struggles with loved ones? When should people tell others about their mental health challenges? Is it ever best not to share?

# It Is Never Too Late to Turn the Page and Rewrite the Story of Your Life

Konstantinos Manthos (Translation by Eleni Chatzopoulou), Greece

- 1. Konstantinos writes, "I consider friendship as one of the most important values in my life.... Friendship can make the painful experiences more tolerable, can reduce the fear that I may feel. Friends give me the courage to continue living in a more entertaining way...." What does it mean to be a good friend? In what ways do you think you have given your friend or family member courage?
- 2. For Konstantinos, discussing his mental health challenges is a powerful way to fight bias and stigma. As a friend or family member of someone living with mental health challenges, how do you fight bias and stigma?

## Depression: One Person's Perspective

Craig Marchant, Australia

- 1. Craig experienced his first hallucinations at age 17 but was not diagnosed correctly until four years later. Talk about the time between when your friend or family member's symptoms started and when they were diagnosed or started treatment. What was that period like for you?
- 2. In the early years of his mental health challenges, Craig writes, "I remember mum at one stage asking the doctor if it could be depression, but he replied that children my age didn't get depression. Ha! If only." In what ways does misinformation or lack of information continue to harm the mental health field? Did misinformation or lack of information keep your family member or friend from receiving treatment? If so, how?

# Learning How to Take Care of the Otherness of Myself

Anonymous One, Columbia

- What do you think Anonymous One means by "learning how to take care of the otherness of myself"?
- 2. Anonymous One says, "Knowing that I had bipolar disorder and borderline personality disorder (BPD) was the first step towards my recovery. Finally, someone put a name on my condition so it became true for other people, like my family." In what ways was receiving a formal diagnosis for your friend or family member helpful for you? Did the condition become "true" for you after the diagnosis? In what way?

# My Journey from Psychological Rape to Spiritual Awakening

Fehmida Visnegarwala, India

- 1. Fehmida discusses the importance of spirituality and certain spiritual practices in her journey toward recovery. What roles, if any, do faith and spirituality play in your friend or family member's journey? What roles do they play in your journey?
- 2. Fehmida writes, "The states of ecstasy and bliss during my manic states are only momentary, yet they are transformative. They fill me with a conviction that one is much bigger than just a body and mind." How do you respect your family member or friend

who finds potential benefit in these episodes while managing the practical difficulties or dangers of these challenges?

# On the Road to Get Our Son Cured from Schizophrenia

Luc De Bry (father), Catherine De Bry-Meeùs (mother) & Valère De Bry (son), Belgium

- 1. The De Bry family did their own research to learn more about their son's condition. They found a treatment that worked. What kind of research have you conducted to learn more about your loved one's mental health challenges? In what areas is more research needed?
- 2. Unlike Valère, many people living with mental health challenges do not have access to medical treatment, alternative healing therapies, or families who support them. What barriers to resources exist in your own communities? How have these barriers hindered care for your friend or family member, and how (if at all) have they been able to overcome these barriers?

## The Lost Darn Tea-Time of the Soul

Nataliya Yaneva, Bulgaria

- 1. Nataliya writes, "Having depression is a peculiar experience. I wouldn't go so far as to say I'm grateful for it but I certainly learned a great deal from living with it.... I've learned to be more tolerant, more patient, more compassionate, and thoughtful. I wouldn't be the person I am today without my anxiety and my depression." What lessons have you learned from caring for or living with people with mental health challenges?
- 2. Nataliya ends her story with a quote by Andrew Solomon, who says: 'Every day, I choose, sometimes gamely and sometimes against the moment's reason, to be alive. Is that not a rare joy?' What small and rare joys give you strength to continue caring for or supporting a friend or family member with mental health challenges? When they may not be improving, what motivates you to continue on?

#### Living to Die: On Chronic Suicidality and the Authentic Self

Michael Nair-Collins, United States of America

1. Michael says, "'You are not your illness' is a common refrain in mental health circles, and I don't buy it. I don't deny that my brain and emotional, cognitive, and behavioral functioning appears different from many others, nor that these differences have caused me severe difficulties in life. But the only conclusion I take from this is that I am neuroatypical: my brain/mind is not "typical" (whatever that means). But the fact of my neuroatypicality does not imply that I must accept the disorder model for explaining my authentic self, a model that denies the richness of my experience, including all the pain and all the joy, as genuinely mine, as authentic aspects of myself. The disorder model shrugs off these experiences as pathological, to be gotten rid of or "managed." This framework sees much of my life's experience as nothing but "dysfunctional biochemical"

- activities" and not my authentic self. I reject this idea thoroughly and completely." Do you agree or disagree that mental health challenges are part of one's "authentic" self? Why? What do you see as strengths and weaknesses of the disorder model (that is, the thinking that mental health challenges are a disorder that need to be fixed, rather than the thinking that mental health challenges are a part of who you are)?
- 2. Michael reflects on the effect his suicide would have on family and friends and says, "I will leave my family and friends to go on living without me, carrying the grief and loss, the pain, the lack of understanding, perhaps guilt.... This aspect of suicide has, in the past, given me enough space to take the first, critical step back from that terrible brink. But I also know that is not enough in the long term—one cannot live solely out of obligation to others." Have you had conversations with your friend or family member about the impact their suicide might have on you? What was difficult, powerful, or meaningful about those conversations? Do you feel as though your friend or family member is living "solely out of obligation to others?" In what ways?

#### Motherhood, Work, and Mental Health: One Woman's Journey

Karin T. O'Brien, United States of America

- 1. Karin discusses the challenges of managing her mental health while having a career and also being a mother. How do the pressures of work and family life affect mental health? How do you help family members or friends balance competing demands?
- 2. Karin writes, "I understand needing to provide accommodations to people with physical disabilities—but realizing there may be a framework to assist me with a mental disability is the next step in my journey." Has your friend or family member ever tried to get an accommodation for their mental health challenges? Were they successful? What challenges did they come across in trying to get an accommodation? How has the accommodation helped them? If they have not tried to get an accommodation, why not?

#### A Portrait of Trauma

Armando Quiñones-Cruz, Puerto Rico

- 1. In the early stages of seeking treatment, Armando writes, "The doctor would change the diagnoses every other month from post-traumatic stress disorder, borderline personality, bipolar disorder, and general anxiety. This constant change and unstructured therapy made me skeptical and wary, missing a lot of appointments and medications." Did your friend or family member experience these difficulties? How can mental health providers better support patients and families during the time when they are waiting to get a correct diagnosis?
- 2. Armando says, "[R]ecovery is an ongoing effort." In the context of mental health challenges, what does recovery mean to you? Is curing mental health challenges possible? If so, how? If not, why not?

# A Soldier's Unseen Scars

Jason Jepson, United States of America

- 1. At one point, Jason's parents called the police because he had become a danger to himself and to others. Talk about a time when you called the police (or almost called the police) because of a mental health crisis. How did they handle the situation? Was this a positive or negative experience with law enforcement?
- 2. Although Jason is now "in recovery" and is learning to live with his mental health challenges, he writes in his poem: "There is still fear." As a family member or friend of someone with mental health challenges, what fears do you have? How do you address these fears so that both you and your loved one can "live out loud?"

#### **Half Dead**

Jessica Morgan, United States of America

- 1. Jessica writes, "I grew up not understanding what mental health was....When I thought of mental health, I didn't see my face." In your opinion, how do we address this lack of education and awareness in our everyday life? How do we make mental healthcare and mental health challenges more visible?
- 2. Jessica says, "I wanted to adhere to the strong Black woman archetype so bad. I wanted to be superwoman, but I couldn't." What archetypes or stereotypes prevented your family member or friend from seeking mental health care? How do we break down these stereotypes to make mental health care more accessible, both socially and practically?

#### **Embodying Bipolar**

Julia Knopes, United States of America

- 1. Julia explains, "My family's socioeconomic status buffered my disability so that I could function, allowing me to spend summers and evenings without employment, free to rest. Privilege softens the ground upon which people with mental illness fall, but if one is dropped from the towering heights of mania, they will still shatter when they land." How has their race, culture, or class helped or hindered your friend or family member's ability to function while living with mental health challenges? What systemic issues need to be addressed so that all people, regardless of status or privilege, have access to mental health resources?
- 2. Julia was "willing to attend therapy" because "it felt characteristic of liberal, educated white women like myself: listening to NPR, sipping water out of reusable bottles, paying for the luxury of professional validation." Was there a time when your friend or family member was "going through the motions" of treatment but was not yet ready to confront the reality of their serious mental health challenges? How did they move beyond seeking "professional validation" to meaningful change?

# Seeking Balance and Recovery in a Life Near People Who Care

Nikolaos Kougioumtzis Stopy (Translation by Valentini Bochtsou), Greece

- 1. Nikolaos worked in a vocational agriculture program for many years and found the work fulfilling. What programs or resources (beyond psychotropic medication) have your friend or family member found helpful? What did they find valuable from these types of programs?
- 2. For Nikolaos, sharing his story is an important part of his healing journey. In what ways are family members and friends of people living with mental health challenges discouraged from sharing their stories? In what ways are they encouraged? Share your story with your group in as much detail as you would like, then reflect on that experience. What was helpful about sharing? What was difficult?

#### Your Unique and Beautiful Brain

Sara Schley, United States of America

- 1. During a crisis, Sara calls her "brain buddy," and they make plans for immediate next steps. How do you help a family member or friend when they are having a mental health crisis? What are the steps in their crisis plan?
- 2. Sara discusses the importance of gratitude, discipline, and compassion on her journey to recovery. As a family member or friend, what role do gratitude, discipline, and compassion play in your life?

#### On Suicide and Survival

Anonymous Two, United States of America

- 1. When their depressive symptoms began, Anonymous Two tried to believe "I can get through this on my own." In what ways did your friend or family member exhibit a similar belief? What prompted them to finally seek help?
- 2. Anonymous Two writes, "Admitting that I needed psychiatric hospitalization felt like I had hit rock bottom. I cried not because I was so depressed, but because I felt like I had failed." Why would having mental health challenges be seen as "failing," and how do we get rid of this view?

# Behind the Iron Curtain of Duty

Monica Gupta, India

1. Monica writes of her friends, "Their non-judgmental approach, perseverance, and constant assistance helped me regain my lost world." In caring for friends or family members with mental health challenges, what qualities or values do you find most important? Have any of your friendships or relationships with family been strained because of their mental health challenges? If so, in what way?

2. After "being on an emotional roller coaster" for seven years, Monica "realized the power of surrender." What do you think she means by this? What does the power of surrender look like in your own life as a family member or friend of someone living with mental health challenges?

#### Double Life

Samantha René Merriwether, United States of America

- 1. Samantha writes, "Currently our mental health system is set up to put people in boxes and label them, which makes it even harder to get help. It is limited by how you fit in the box and what type of treatment you qualify for in conjunction with your insurance." To what extent do you agree with Samantha's assessment? How do we move beyond "labeling" to help those living with mental health challenges?
- 2. Samantha talks about "being her own advocate" and "learning new ways of coping." How do you help your friend or family member advocate for themselves? How do you advocate for them when they cannot?

# Second Changes for Bipolar Women: Coming Out of the Dark, a Life Under Construction

Imelda Caravaca Ferrer, The Philippines

- 1. For Imelda, writing and poetry are important aspects of her healing journey, and many of the authors included poetry in their stories. How, if at all, is art a healing therapy for you or your friend or family member?
- 2. Imelda writes, "people are afraid of things and people they don't understand." As a society, how might we improve awareness and understanding of people living with mental health challenges? What could you do as an individual to improve other peoples' awareness and understanding about mental health challenges?