

The phone rings at 9:00 on a Tuesday night. My wife hands me the phone. “It’s your mom” she says with a concerned look that makes me hold my breath. This late at night can only mean one of two things; someone has died, or the more likely scenario, my younger brother Jake is having some kind of trouble. This is how it goes, how it has gone for as long as I can remember.

Jake lives with multiple mental health disabilities, a 33-year-old body, with the mental state of about a 15-year-old. A traumatic brain injury in his 20’s that nearly killed him and the alcohol that his birth mother drank while she was pregnant with him can make interactions with and for him a challenge. Our family isn’t so unique though. We are merely one of the millions of families living in the ravages of America’s growing mental health crisis. Hidden, ignored, shamed and left to navigate underfunded, undereducated, and incongruent systems that rarely provide adequate help.

For people who like numbers; some statistics for you from NAMI, the National Alliance on Mental Illness:

- Approximately 1 in 5 adults in the U.S experiences mental illness in a given year.
- Approximately 1 in 5 youth aged 13–18 experiences a severe mental disorder at some point during their life.
- An estimated 26% of homeless adults staying in shelters live with serious mental illness.
- 70% of youth in juvenile justice systems have at least one mental health condition.
- Only 41% of adults in the U.S. with a mental health condition received mental health services in the past year.
- Serious mental illness costs America \$193.2 billion in lost earnings per year.
- Suicide is the 10th leading cause of death in the U.S., and the 2nd leading cause of death for people aged 10–34.

- Each day an estimated 18-22 veterans die by suicide.

Despite its widespread impact on nearly every American family, either directly or indirectly, mental illness is rarely spoken about openly.

While there are many reasons for this, I have a hunch that it boils down to two main factors; fear and shame.

Mental health has been used over the centuries as weapons, especially against minorities and women, millions of whom were confined to sanitariums because they weren't "obedient" enough, or they were just plain in the way. Fear is a powerful motivator!

After I had my daughter, the depression and anxiety I had lived with since I was 16 went into hyper drive. What started out as a serious case of the baby blues, the massive hormone battle to rebalance after pregnancy that leaves some women in a state of profound stress, sadness, fear and anxiety, turned quickly into a case of postpartum depression. NO ONE had told me anything about the baby blues, not my friends, my family or my doctors and nurses. No one! Not every

woman experiences it, but for those that do, the baby blues are scary and traumatic, especially if you haven't been warned about the possibility, the time frame and the ways to ease through it. After the extreme emotional roller coaster of the blues passed, a deeper sense of dread and anxiety set in.

I started my professional life as a trained social worker, so when I was given a post-partum questionnaire to fill out at the pediatrician's office a few weeks after my daughter was born, I knew the "right" answers to mark. By "right" I mean the answers that wouldn't arouse any suspicion that something was wrong. See that's the thing about mental illness, it lies to you. It tells you that you can handle it, that if "they" find out, they will take your baby away from you, after all you are a lesbian in the south, what more proof do they need that you are unfit. The fear and shame I felt during that time, set me on a year long path of depression that robbed me of so much joy with my child. Looking

back now, I wish I could have asked for help, I wish I could have been honest, I wish there had been more than a questionnaire.

Fears sneaky little cousin is shame. While I would like to thank Hollywood for this one, it's not all their fault; though they share a fair amount of blame for our more modern perspective on mental illness. American's are obsessed with entertainment for entertainments sake, and characters with mental health challenges make for great bolder than life, scary villains to haunt our dreams. Or quirky detectives whose eccentricates are the key to solving the mystery. Or the comic relief whose mania keeps us laughing every Wednesday night. These characters tend to be defined by their mental illness, but without the full fleshing out of the realities that come with living with these specific challenges. Missing are the years of misdiagnosis, the cycles of medication trial and error, the highs and lows outside of the story line, the lack of adequate and timely treatment, the outrageous expense for that treatment and the alienation of family and friends.

Shame is also rooted in our societies desire to always show our strength. With other illnesses we are more than happy to rally around the “victim” who is being ravaged by the unfair fates of life. We bring casseroles to the cancer patient, we sit and chat at the bedside of the lung patient, we send cards to a wrecked body after a traffic accident. These are survivors who are strong, brave and worthy. If they succumb to their illness or injury, we say that they “fought the good fight to the end”, they are our hero’s and saints. They were so strong and never gave up.

Mental illness isn’t usually afforded that same care, grace and praise. It actually tends to be the exact opposite. People struggling with mental illness are often seen as weak, lazy, and attention seeking. We whisper about their “break-down”, but don’t send a casserole. We shake our head about their struggle, but we tire easily of their story. We don’t ask how they are doing, because they just might tell us the truth. When they succumb to the ravages of their illness, far to often by suicide, we shake our heads, and ask why they didn’t reach out, or say if they had

just been stronger, they would have seen life was “worth” living, they are seen as selfish for “giving in”.

Mental health plays a long game, with few to no short cuts. Humans are not known for our patience or our attention spans, so it makes some sense that we have yet to dedicate a fair share of funding and research to the study of mental health...we simply don't find it sexy.

The phone rings at 11 in the morning on a Friday. It's my mom. Jake is doing really well she says, he's been fairly stable for a few weeks, she is hopeful that we have turned a corner. I wish I could share in her hopeful optimism, we both want so much for him to be stable, happy and find joy in life. However, 33 years of advocating on his behalf has taught me a cautious optimism, tinted with a healthy dose of skepticism.

If you ask Jake, I'm the favored child., the one our mother never has to worry about, the successful one, the stable one. If you ask me, I used to feel like the forgotten child, our mom's energy, times and money

was needed to help Jake maintain a somewhat level plane of existence. There was no room for me to be anything other than okay, self sufficient and responsible. This is an all too common dynamic in families that live with mental illness. The push and pull between the love we have for the one trying to cope, and the anger and resentment we feel for all that it takes from us.

Please don't get me wrong, I don't resent my mom, and I don't hate my brother. While his illness often dictates the dynamics of our family, Jake is so much more than his mental illness. You will never meet a kinder heart. His love and care of the young and the elderly tells me all I really need to know about him. His desire to understand how everything works and his child's eye for the world is endearing.

I do however, resent the system that doesn't provide support, and makes it next to impossible to find any kind of long-term cohesive stability. I hate the lack of equitable funding to find new treatments and medications that don't rob their users of a fulfilling life because of

dramatic and painful side effects. I'm angry at our criminal justice system, that fails to provide even remotely adequate training to its officers about the realities and best practices when working with people living with mental illness. I'm furious at the legal system that turns a blind eye to the need for common sense laws that take into account the mental health of those who enter the system. And I'm devastated that our denomination has failed to treat mental illness concerns as the social justice and accessibility issue that it is.

The phone rings at 6:45 on a Monday evening. I can barely understand my mom as she tries to breath and talk through her tears. She is overwhelmed and exhausted again. Jake has been arrested on a possession with intent to sell charge. Mom just can't do it anymore, the constant swing of stable to trouble, to stable to manic, to stable to depressed. I tell her we'll figure it out like we always do, but I'm never really sure if this is the time, we won't figure it out. I live in a perpetual state of fear of the phone ringing, not because of the calls about my brother, but

because I know one day the call will be to tell me the stress on my mom was too much. This is the life of family and advocates.

This time Jake was stopped while walking down the street, the police asked him if he had drugs on him; he was always taught not to lie so he says yes. They find 3 small bags of marijuana. he had been off medication for a while because getting an appointment with psychiatrist can take months to secure. Even then, the meds make him groggy and he can't think, so he often self-medicates with pot.

He tries to explain that he's not going to sell. If you know Jake and his mental illness and short-term memory loss, you know that 3 smalls bags make perfect sense to him. He's afraid he will lose it or be robbed; always have a backup or two...paranoia at its finest. He enters the criminal justice system again, where he racks up a huge bill just for basic necessities and medical treatment that they require upon entering the system. This bill will be paid by mom, Jakes disability check barely covers his housing. She already supplements his monthly check,

since those getting disability don't qualify for food stamps. They give him a new med this time, with new side effects, and then blame him for the mania and disordered thinking that comes with it. His paranoia prevents him from participating in his own defense. Mom pays the bail to get him out, and he end up taking a plea to avoid going back to jail. Round and round on the merry go round we go...but no one is enjoying the ride.

In a mental health crisis, people are more likely to encounter police than get medical help. As a result, 2 million people with mental illness are booked into jails each year. Nearly 15% of men and 30% of women booked into jails have a serious mental health condition.

Once in jail, many individuals don't receive the treatment they need and end up getting worse, not better. They stay longer than their counterparts without mental illness, and they are at constant risk of victimization by other inmates and guards.

After leaving jail, many no longer have access to needed healthcare and benefits. A criminal record often makes it hard for individuals to get a job or housing. Many individuals, especially those without access to mental health services and support, wind up homeless, in emergency rooms and often re-arrested. At least 83% of jail inmates with a mental illness did not have access to needed treatment at the time of their arrest.

Without adequate and consistent treatment, far too many with mental illness make the choice to end the cycle by ending their lives. According to the CDC, suicide rates have increased by 30% since 1999. Nearly 45,000 lives were lost to suicide in 2016 alone. Studies also suggest that nearly 90 % of people lost to suicide did not have a diagnosed mental illness at the time of their death, but showed symptoms. These numbers suggest that access to comprehensive diagnosis and treatment is seriously lacking. We are also seeing a rise in mental health concerns among primary care givers and families of those living with mental illness. Depression, anxiety, and post-traumatic stress disorder resulting

from the trauma of day to day unsupported care for family members with mental illness is rising at alarming rates. All these numbers don't even touch on the increase in substance abuse patients that are self-medicating.

Advocacy groups are often made up primarily of the families supporting those living with mental illness, who have come together in desperation and necessity to advocate for change. These families are already emotionally exhausted, financially strapped and generally unsupported by their communities. They live in silence and shame, forgotten about and suffering alone.

In 1961, the general assembly of the Unitarian Universalist Association passed a resolution that directed congregations to study the mental health services available in their communities, and to advocate for expanded services and compassionate care for those living with mental illness.

Now nearly 60 years later, we as an association have done little to shine the light on mental illness and mental health advocacy within our congregations and our wider communities. The work of our Beyond Categorical Thinking teams shows that concerns about mental illness remain one of the number one issues that congregants have profound hidden bias around when thinking about hiring a minister.

In 2011, the Rev. Barbara Meyers began a mental health ministry at Mission Peak UU in Fremont, CA to provide support and ministry to those living with and loving people with mental illness. Rev. Meyers also wrote a curriculum, *The Caring Congregations Handbook*, to assist congregations in mental health ministry. I've have had the pleasure of meeting Rev. Meyers on numerous occasions and I admire her dedication and commitment towards establishing mental health as a social justice issue.

If you google, mental health UUA, you will find many articles about individuals, like Rev. Meyers, doing great things over the years towards

supporting our mental health communities, but my friends, this is not enough. We need an organized, loud, and compassionate movement to bring forth the issues around mental illness that touch us all. We need dedicated, open conversations spaces that allow for honest dialogue for caregivers needing support. We need ministries in the majority of our congregations that understand the intricacies and roadblocks to mental health care and can provide direction to services and agencies providing help. We need vocal and knowledgeable social justice advocacy for the homeless and prison populations, for respite care for caregivers, and for changes to our healthcare funding systems to open low cost treatment options. We need to do more, we need to say something!

It's Friday afternoon and I let the phone ring to voice mail, to be honest I usually let Jake's calls go to voice mail. It's easier, you know, I can generally judge his mental state by the message he leaves. I'll answer by text message, it's easier to keep him on track that way. He had been

manic and paranoid the day before, mad that I had been so honest with the judge about his inability to hold a job for the long term. The message tells me he is lucid and calm, “Hey Sis! I know we don’t always see eye to eye, but I wanted to say thanks for helping me with the Disability hearing. I know you didn’t have to do it, but it means a lot to me. We really should talk more. Well, I love you, sis.” He knows I will continue to fight, to advocate to push for more visibility and better services, because his life, my mom’s life, like millions of others, depends on it.

Our values call on us as Unitarian Universalist to set the table for all, to make the door wide enough to get through, and to recognize our connections to all beings. We are called upon to raise our voices and use our talents to ensure that the welcome table is big enough, strong enough and inviting enough to host the world. It is our call to offer support and advocacy, it’s far beyond the time that we answer the phone in regards to mental health advocacy.

A few months may pass fairly quietly, and those times of stability are always a welcome respite... (Phone rings) and then the phone rings.

This is how it goes for so many families like ours.

Amen and Blessed Be