

“It’s Not a Casserole Illness”

A Sermon by
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with **Karen Schiller and Helene Iverson**

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Call to Gather: Now I have no choice but to see with your eyes – so I am not alone, so you are not alone.
~Yannis Ritsos

First Reading:

There are enough people out there who still equate mental illness with damaged goods that can't be fixed. We make jokes about being crazy – it's part of our lexicon. Someone acts strangely – they're crazy. They have the scarlet letter on them and that's that. I emphasize that people should not be ashamed of mental illness, that they don't need to talk about it in hushed, conspiratorial tones. That's why I think it's important for people who are well known to speak out and reinforce for those who don't have famous names that they are part of a club that is a healthy one...or can be. ~ Patty Duke

Second Reading: “To Love Life” by Ellen Bass

*The thing is
to love life, to love it even
when you have no stomach for it
and everything you've held dear
crumbles like burnt paper in your hands,
your throat filled with the silt of it.
When grief sits with you, its tropical heat
thickening the air, heavy as water
more fit for gills than lungs;
when grief weights you like your own flesh
only more of it, an obesity of grief,
you think, How can a body withstand this?
Then you hold life like a face
between your palms, a plain face,
no charming smile, no violet eyes,
and you say, yes, I will take you
I will love you, again.*

Sermon:

DOTTIE: It was the middle of the night in May of 2006. I was in the Twin Cities, feverishly completing my seminary's final exams, and wrapping up my Internship. I exhaustedly laid my head down for what I knew would be desperately needed (but far too little) sleep only to be interrupted by the sound of my cell phone ringing, rousing me, ever so reluctantly. My heart sank as I saw the time: 3:00am! "Now what!" My eldest, my son, Philip, had been calling me at odd hours, needing to talk about one thing or another, all seemingly quite UN-urgent in my estimation. I was concerned, of course-; but repeatedly quieted my own fears. "He's probably OK," I thought. "He's a little eccentric and tends to get worked up over things. He's just over-stressed now from being out of work for so long."

But the moment I heard his voice, I knew this was different. His rapid fire speech was punctuated with weeping gasps, crying from his depths. When I calmed him long enough to decipher what it was he was trying to tell me, I came to understand that he was convinced that he was about to be martyred and - this was the part that had him so upset - that I, as his mother, was also in mortal danger from those same phantom assassins.

His terror was palpable. I was able to eventually soothe him enough to learn his whereabouts and I told him to remain exactly in that spot. I contacted my brother who thankfully lived nearby; he picked Phil up while I arranged to fly to California, having no idea what I'd encounter when I arrived. All I knew was that my much-loved son, "my guy" as I had called him for nearly 30 years, was in deep trouble and I had no idea how OR IF I could help. But I held a mother's conviction that I was surely going to try.

This true story might take many of you by surprise. You've known that I have children - I've made reference to the three of them several times from this pulpit, but I haven't yet discussed this aspect of our family's life in such an open forum. Several of you have heard bits of his story in smaller venues, but for many reasons, it seems right to share it from the pulpit today.

Every week, I am profoundly reminded that one of the reasons we come together here in this sacred community is to talk about the truth of our lives together, the truth of our experiences - the great, the terrible, the difficult, the celebratory, the sad; and to grapple together to deepen our faith so that we can – together - find enough courage and tenacity and hope to carry us through those real life experiences.

Now, if we hold true to national statistics, about 20 or 25% of us gathered here today have experienced a serious diagnosable mental illness¹ and, if that portion of our community has personally experienced such illness, then many, many more of us love someone who has endured - or is enduring - that kind of struggle. We just don't often share it widely. Instead, what we know is that mental illness continues to be shrouded in enormous ignorance, cruel humor, misinformation, terrifying myths, disproportionate fear, and, most especially, shame - silencing, stifling, suffocating shame.

It is our hope – mine and Karen's and Helene's - that at the very least, we can today, within this loving community, lift that dark veil off and allow ourselves to imagine a world where people are invested in caring well for one another, rather than hiding away the realities of these illnesses and their exponential impact on our society. This is what has brought Karen and Helene here today – to offer their story in the hopes that it might be useful for others. I give you now, Helene Iverson and Karen Schiller

¹ <http://www.nimh.nih.gov/health/publications/the-numbers-count-mental-disorders-in-america/index.shtml>

KAREN: My name is Karen Schiller and my struggle with mental illness began almost ten years ago. My symptoms began to emerge when I was in college but I was able to “hide” them and live with my illness. I graduated from the University of Minnesota, got married, started a career and got pregnant. I had a difficult pregnancy and we were living in Rochester, New York at the time. After my son, Nick, was born, things began to fall apart. We were separated from family which made things even more difficult.

HELENE: My name is Helene Iverson. I am Karen’s mother. My first encounter with Karen’s mental illness came in the middle of the night in 2004 with a telephone call from Rochester, NY. She had just delivered our first grandson, Nicholas 3 days earlier, and was talking a mile a minute about how we were going to have to read a lot of books about how to be grandparents, about how our relationship was going to change, and a million other things. We couldn’t get a word in edgewise. My husband and I hung up the phone and said, “What the hell was that all about?” We stayed awake that night wondering what had happened to our University of MN valedictorian daughter. Who could we discuss this with? We didn’t know any psychiatrists here. Should we talk to someone at an Appleton hospital? Would a call to United Way give us some help? God intervened and had a friend call us for dinner and guess what...he was a counselor. He interpreted what we had heard as a psychotic break and told us what to expect when we flew out to see Karen. After we learned that Karen has bipolar disorder, we began to learn more about mental illness and how we could support her.

KAREN: Things became so difficult that my husband and I had to quit our jobs and move to be closer to family. We moved back to Appleton. At that time my illness was severe to the point that I was hospitalized multiple times and went through a substantial number of medications and ECT/shock treatments. For two years I struggled with my illness and was pushed to the edge many times with thoughts of wanting to die and end it all.

HELENE: On one hand, when Karen, Jay and Nick moved back, we were excited as any first time grandparents would be to watch our grandson grow. On the other hand, we were forced to become his second parents because of the chaos in Jay and Karen’s lives. When Jay went back to work full time, we were caught between caring for a toddler and caring for our daughter who seemed lost to us. How could a new mother with such a beautiful child not be able to see any hope? Would we ever get our daughter back? Would we ever get our lives back?

KAREN: Through trial and error, I began to find things that worked for me. We found a combination of medications that began to get my symptoms under control. I started exercising which helped to heal my body, mind and spirit. I got involved with NAMI – the National Alliance on Mental Illness. One of the things that jump started my recovery journey was completing the Peer to Peer course, a free course offered by NAMI for consumers that educates individuals about mental illness, recovery principles, resources and coping skills. During this time I was able to meet some recovery role models, people who were living well with their illness and were able to help others by using their own recovery journey. During this time I thought, wow, I can do this! NAMI helped connect me with resources and provided vital peer support. I no longer felt alone in my struggles, I found people who understood. The support of my family and friends was invaluable throughout my recovery...when I didn’t have hope, they held hope for me.

HELENE: My husband and I took NAMI’s 12 week Family to Family course and learned so much about the physical and emotional toll that this illness was taking on Karen, her husband, and us. We learned that we were not alone, that the stress we were feeling was not unusual, and best of all, we made friends that are walking

along side us on this life long journey. I have become an advocate for those with brain disorders. I coordinated a series of articles in my church's bulletin about mental illness and since have been contacted frequently by people in my parish. I am part of a team that carries the NAMI cell phone to take calls when the office is closed. In my life, I work to break the stigma around mental illness by talking about it, sharing our story and educating others.

KAREN: In 2007, I was able to return to work, I am the development director for the Housing Partnership in Appleton. I am the proud Mom of a five year old in kindergarten. As my journey continues, I use my recovery to help others by facilitating a peer support group at NAMI and I have also taken a position with the state of Wisconsin to train consumers on becoming empowered to work with their providers to reach toward their goals and dreams. I continue my journey in recovery and am living well with my bipolar disorder, but it will always be there, much like cancer in remission. I celebrate each healthy day and hold hope that someday medicine will be able to prevent others from struggling with mental illness.

HELENE: Things have changed in the five years after that telephone call in the middle of the night. There have been bad days, there have been unimaginable horrible days but today Karen's illness was not the first thing I thought of when I woke up. My husband and I have been able to resume our "normal" lives. We are grandparents, not parents. We're able to travel, spend time with our friends and pursue outside interests and just do nothing if we want to in our "recovered" free time. I feel like we have our daughter back.

KAREN: I am a person of faith, and I believe that there is a reason for what happens in our life. For a long time I searched for answers for all of this and questioned why this happened to me. Today I believe that the reason for my struggle is to share my recovery journey and to stand here as a messenger of hope. I know that many of you here today have been touched by mental illness, maybe you have struggled with it, maybe a family member or friend has. We wanted to share that recovery is possible and there is hope. Thank you.

DOTTIE: I don't know how many of you caught the meaning behind the name of this message - Our chosen title of "It's Not a Casserole Illness" actually came from Helene. Those of us who have experienced a crisis with our loved ones' mental disorder, get the meaning all too clearly. In most settings, if your spouse or child is hospitalized for a heart condition or dialysis treatments or even some relatively minor surgery, one-dish dinners and Get Well cards & phone calls abound. But when your loved one is on a court ordered hold in the psychiatric ward, the most common response from all but the closest family and friends is silence and avoidance. It's just too uncomfortable or frightening for many people to talk about. And there is an element of complicity in that silence, coming in part from the conscious and unconscious blame and humiliation that is groundless but has long surrounded mental illness. The feelings are so complex; people hardly know what to say to one another.

Now, I am grateful that here at the FVUUF, we do bring casseroles at times such as these; maybe we can help launch that trend into the wider community. As a congregation we are devoted to always and ever Standing on the Side of Love and one of the first, most loving things we can do is to work to break that stigma. There are many agencies raising awareness and providing education. Four of them are listed on the Resources section of the Order of Service². Please do contact these folks for more information because it's important that we each

² See Appendix

take responsibility to educate ourselves and to create the space where these difficulties can be discussed openly and without embarrassment, no more than one would be embarrassed to talk about heart disease or kidney failure! Illness is illness!

In that education, we'll become more aware of our language and how we talk about these disorders. The person is much more than their mental ailment. We should avoid saying someone "is bipolar" or "is schizophrenic." When we do that, we are diminishing that person down to nothing more than their diagnosis. We would NEVER say someone "is cancer!"

A person dealing with mental illness is a person who has a family, hobbies and interests, dreams, perhaps a vocation that is calling them. They are so much more than their diagnosis.

In addition, we know that we often unthinkingly hurt others when we make jokes about people being "crazy" or needing to go to "the funny farm" or acting "psycho." Given the statistics, there's a pretty good chance that someone who is personally affected by this is in ear shot. For some, these terms may seem like harmless banter among friends, but they express an underlying societal disapproval that runs deep and is very hard to counter. And that disapproval is often one of the factors that discourage people from seeking the very treatment they need.

Another thing we can do is hold onto hope and share that hope with others. We heard Karen's story - how she's been able through her hard work and the support of good people to assume responsibility for her own health. She continues to be vigilant so that she can retain this beautiful life she's built with her family within the community. Hers is a great story but it's important to remember that she's not alone in her recovery! Many others have similar stories. And, even for those of us who have loved ones who have not yet found that kind of stability, we can be the bearers and promoters of the good news that recovery is possible.

Believe me, I know, it is so hard to hold onto that hope sometimes. It's so very wearying to "hang in" with someone who determinedly avoids the very help she or he seems to need the most.

It can be infuriating when the symptoms emerge in dangerous behaviors, like driving too fast, running up debt, self-medicating with drugs and alcohol (which is exceptionally common and is prevalent in my son's case) or other kinds of self harm.

It can be thoroughly disheartening when the person seems to "play along" with medical advice, promises to take the prescribed medications and, then as soon as the improved moods take hold, they go off their meds and the chaos returns.

These things can break loved ones' hearts and, for many, make it quite a spiritual practice to try to maintain any sort of ongoing relationship with the person, or to hold onto the faith that tomorrow might be better.

One of the best things I got out of preparing for this sermon was the strong recommendation from both Karen and Helene for the book I Am Not Sick – I Don't Need Help (see Resource list). This book describes at length is that a hallmark symptom in many cases is that the person may appear to be exasperatingly stubborn and defensive. Unlike other life-threatening diseases, it is extremely unfortunate that the person's brain chemistry is actually altered by the disease, often causing them to have little or no insight or understanding into the gravity or consequences of their illness.

This makes it so much more difficult to know our role as a family or friend of a person dealing with these disorders. If you learned your spouse or child had lupus, for instance, there would be an immediate collaboration between the patient, their care team and the family as everyone worked together to overcome the effects of disease.

But it's very different with mental illnesses and it's crucially important to remember that the ill person frequently truly does not know. They're not just being intentionally obstinate. The way their brain chemistry is functioning by definition alters their perceptions of the world. It's physiological. Just like any other medical condition, it is not something one can be argued out of nor can we simply force the person to seek treatment (unless they are an imminent danger to themselves or others) and, even if we could, except in the gravest of situations, s/he is still an autonomous being with choices about whether or not to continue to participate in whatever care is offered. It is all further complicated by the privacy laws that preclude the medical team from speaking with family members unless the patient gives permission.

As Helene described, for family & friends, there can be great grief because of the feelings of impotence and the fear of losing our loved one forever.

But, the message today is: **Do Not Despair**, whether you are dealing with this or if you love someone who is. Because it is a medical condition, in many cases, with the right treatment (which, we know, is no small task to find) in many cases it is something that can be effectively treated.

Now, perhaps you are here and you don't happen to have a life that is directly touched by mental illness. Is there reason for you to have an investment in this growing social issue? Absolutely! According to our government's estimates, between 50 and 60% of all incarcerated persons in the U.S. - that's local jails, county, state and federal facilities - have symptoms of serious mental illness³.

I was told by a Los Angeles Social Worker after my son's most recent arrest that their county jail has de facto become their largest mental health facility. Do you know what it costs taxpayers to house and care for a prisoner as opposed to providing monitored mental health services?

Beyond that, the lost productivity in the American workforce is enormous, especially when you necessarily include the impact on family members. The December 4th issue of Business Week has an article devoted to this⁴ that offers this highlighted quote: "It's hard to focus on your work when your child is hallucinating."

Our society loses in worker productivity, we lose in the high cost of ever-larger jails for people whose real crime is mental illness, and we lose of course by the literal loss of life. We know that persons dealing with depression and bipolar are 12 to 20 times more likely to die by suicide than others are. "Tragically, [one report notes] suicide is a fatal response to a treatable illness..."⁵

It seems we need to grow in maturity on this subject as a society and throughout the world. I'm curious about something. In my research I came across a piece of news that had somehow completely passed me by. How many of you knew that Winston Churchill dealt with bipolar disorder. It's documented in several sources; he labeled it his dreaded "black dog." A few years back, a statue went up in England to commemorate this. It

³ http://www.nami.org/Template.cfm?Section=Top_Story&Template=/ContentManagement/ContentDisplay.cfm&ContentID=38174

⁴ "The Hidden Business Cost of Mental Illness" http://www.businessweek.com/managing/content/dec2009/ca2009124_395378.htm

⁵ <http://www.stopasuicide.org/suicide.aspx>

had Churchill standing with a forlorn look, bound in a straight jacket⁶. The statue was commissioned by a mental health advocacy group because they wanted to dramatically display how people with mental illness are discriminated against and unfairly limited in their opportunities. The straight jacket was metaphoric, intended as a stark contrast to Churchill's numerous accomplishments. But the statue caused such an uproar! People were so insulted that they dared to show this, that it was quickly removed from the public square.

I share this because (1) I hadn't realized Churchill was another of the many people who accomplished amazing things despite dealing with mental illness and (2) the debate around the statue is so revealing. People were so incensed that this aspect of his life would be emphasized in this way. The statue lasted three days I believe and, as far as I can tell, is no longer on public display anywhere. Interesting!

So I will to end this with a brief point on acceptance. Mental illness is no different than other illnesses in that if we were to have the option, we would all choose to remain bountifully healthy in body, mind and spirit – and have our loved ones the same. But just like other ways human bodies uncontrollably break down, there is an enormous amount of this that is utterly out of our control. It cannot be wished away. It cannot be argued into submission. There is however, great hope with right treatment and the love and support of others.

I urge us all to become educated and hope-filled advocates for those who deal with mental illness. The consequences to our society are far too great for us to turn our backs on this growing crisis.

And if you are struggling with mental illness yourself, or if you, like me, love someone who is, and you long with all your being that he or she might find that path to recovery, try hard to hang onto hope. Reach out to others who understand and, in the midst of the struggle, it is so very important to still cherish life – yours and theirs. As our reading from Ellen Bass urges us: The thing is to love life, even when you have no stomach for what it has handed you, even when you are, as she said, weighed down by the obesity of grief.

Do not give up.

You are not alone.

Amen.

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⁶ http://www.bbc.co.uk/stoke/content/articles/2006/09/20/bipolar_disorder_churchill_feature.shtml

Appendix of Suggested Resources:

NAMI (National Alliance for Mental Illness) www.nami.org . Locally: 516 West 6th Street, Appleton, WI 54911 (920) 954-1550

Depression and Bipolar Alliance www.dbsalliance.org

Wellness Recovery Action Plan resources by Mary Ellen Copeland

www.mentalhealthrecovery.com

National Mental Health Information Center 1-800-789-2647

Books & Magazines:

I Am Not Sick – I Don't Need Help by Xavier Amador

Closing the Chasm by Benjamin Diven, M.D.

Loving Someone with Bipolar Disorder by Julie A. Fast and John D. Preston

Mind Over Mood: Change How You Feel by Changing the Way You Think by Dennis Greenberger and Christine Padesky

*Living Well with Depression and Bipolar Disorder: What Your Doctor Doesn't Tell You...That You Need to Know*_by John McManamy – see also his website: www.mcmanweb.com:

bp magazine (for Bipolar Disorder) www.bphope.com

esperanza magazine (for Anxiety & Depression) <http://www.hopetocope.com>