

Dr. Kay Redfield Jamison  
DBSA Speaker Program in D.C.  
March 6, 2008

**Part One: The Talk**

This is a report on the highlights of the talk and Q&A period that I attended at Washington University Hospital on March 6, 2008. The speaker was Dr. Kay Redfield-Jamison, a psychologist as well as professor in Psychiatry at Johns Hopkins School of Medicine. She is a prolific author on the subject of mental illness and she herself has bipolar.

All the book quotes are from her biography, An Unquiet Mind: A Memoir of Moods and Madness.

Dr. Jamison is introduced by Kathy Colvin, who volunteered and organized this event. Kathy is so calm, smooth and professional. I am just beaming, being so proud of her. Thanks to Kathy, over 200 people are given this opportunity. You're an inspiration, Kathy.

Dr. Jamison says she has been involved with DBSA from its birth in 1985, which she says has done great things for encouraging science, community and political activation on mental illnesses, and provides excellent support groups. DBSA is the organization that held this event.

Dr. Jamison introduces her talk by saying it would be about what it feels like to have the psychotic form of bipolar, the problems in treating people and keeping people in treatment, and the process of her going public with her disorder.

She says tens of thousands of people die every year from bipolar, and most are young.

“My manias, at least in their early and mild forms, were absolutely intoxicating states.”

“It took me far too long to realize that lost years in relationships cannot be recovered. The damage done to oneself and others cannot always be put right again and the freedom from the control imposed by medication loses its meaning when the only alternatives are death and insanity.”

“The major problem in treating bipolar illness from a clinical perspective is not that there are not effective medications, because there are. It is, rather, that patients so often refuse to take them. Worse yet, because of a lack of information, poor medical advice, terrible (inaudible), or fear of personal or professional reprisals, they do not seek treatment at all.”

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“Manic depression distorts moods and thoughts, insights truly dreadful behaviours, destroys the basis of rational thought, and too often erodes the desire and the will to live. It is an illness that is biological in its origins, genetic, yet one that feels psychological in the experience of it, an illness as unique in conferring some advantage of pleasure, yet one that brings in its wake almost unendurable suffering and, not infrequently, suicide.”

She goes on to say how fortunate she is that she has not died from her illness, that she has had the best available medical care, she can afford care, unlike many Americans, and she has friends, colleagues and family that support her. So she says because of this, she has tried her best to use her experience of this disease to inform research and teaching practices and do advocacy work.

Clinicians are reluctant to make their diagnosis public. She says she had no idea how serious the consequences would be of going public. But she says, “I was tired of hiding, tired of mispent and (inaudible) energies, tired of the hypocrisy and tired of acting as though I had something to hide.”

It has been difficult for her to go public, and she says, “I continue to have concerns about my decision to go public, but one of the advantages of having manic depressive illness for so many years is that very, very little now seems to me insurmountably difficult.” And then she goes on to speak poetically again.

This is something she wrote for the residents, not divulging that it was her own experience, describing what bipolar illness feels like. This is a quote from Page 67-68 of her book: “There is a particular kind of pain, elation, loneliness and terror involved in this kind of madness. When you're high, it's tremendous. The ideas and feelings are fast and frequent, like shooting stars, and you follow them until you find better and brighter ones. Shyness goes. The right words and gestures are suddenly there, the power to captivate others a felt certainty. There are interests found in uninteresting people. Sensuality is pervasive and the desire to seduce and be seduced irresistible. Feelings of ease, intensity, power, well-being, financial omnipotence and euphoria pervade one's marrow. But somewhere this changes. The fast ideas are far too fast and there are far too many. Overwhelming confusion replaces clarity. Memory goes. Humor and absorption on friends' faces are replaced by fear and concern. Everything previously moving with the grain is now against. You are irritable, angry, frightened, uncontrollable and enmeshed totally in the blackest caves of your mind. You never knew those caves were there.

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It will never end, for madness carves its own reality. It goes on and on, and finally there are only others' recollections of your behavior - your bizarre, frantic, aimless behaviors – for mania

has at least some grace in partially obliterating memories. What then, after the medications, psychiatrists, despair, depression, and overdose? All these incredible feelings to sort through. Who is being too polite to say what? Who knows what? What did I do? Why? And most hauntingly, when will it happen again? Then, too, are the bitter reminders – medicine to take, resent, forget, take, resent and forget, but always to take. Credit cards revoked, bounced checks to cover, explanations due at work, apologies to make, intermittent memories (What did I do?), friendships gone or drained, a ruined marriage. And always, when will it happen again?"

Dr. Jamison takes lithium. For the first many, many years of her illness, she was given huge doses of lithium and therefore had serious side effects. Now medical practice is to prescribe less, and she takes less, with less side effects. She wrote a list for the residents she was teaching when she was struggling with the severe side effects of lithium. This is from her book, Pg 97-98:

"Rules for the Gracious Acceptance of Lithium into Your Life:

1. Clear out the medicine cabinet before guests arrive for dinner or new lovers stay the night.
2. Remember to put lithium back into the cabinet the next day.
3. Don't be too embarrassed by your lack of coordination or your inability to do well the sports you once did with ease.
4. Learn to laugh about spilling coffee, having the palsied signature of an 80-year-old, and being unable to put on your cufflinks in less than 10 minutes.
5. Smile when people joke about how they think they "need to be on lithium."
6. Nod intelligently, and with conviction, when your physician explains to you the many advantages of lithium in leveling out the chaos in your life.
7. Be patient when waiting for this leveling off period. Very patient. Reread the book of Job. Continue being patient. Contemplate the similarity between the phrases "being patient" and "being a patient."
8. Try not to let the fact that you can't read without effort annoy you. Be philosophical. Even if you could read, you probably wouldn't remember most of it anyway.

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9. Accommodate to a certain lack of enthusiasm and bounce that you once had. Try not to think about all the wild nights you once had. Probably best not to have had those nights anyway.
10. Always keep in perspective how much better you are. Everyone else certainly points it out often enough, and, annoyingly enough, it's probably true.
11. Be appreciative. Don't even consider stopping your lithium.
12. When you do stop, get manic, get depressed, expect to hear two basic themes from your family, friends and healers:
  - a) But you were doing so much better, I just don't understand it.
  - b) I told you this would happen.
13. Restock your medicine cabinet!"

Then she talks about why madness is so difficult to let go of, and why accepting a diagnosis and the meds is so difficult, as per her book, "Missing Saturn" on Pg 90-91.

Then she quotes her book about her suicide attempt. After her suicide attempt, she became compliant with medication and has been since. "Repeated psychosis, dying, have a way of convincing even the slowest of learners."

Dr. Jamison says she was brought up very private, but "privacy and reticence kills." Before going public, she had written about bipolar for 20 years, was a full professor, and had the support of her friends, family and employer (Johns Hopkins). So she says she thought, if I can't go public, no one can go public.

Dr. Jamison says telling her patients about her illness was easy for her. Most of them remarked how normal she seemed. Telling her fellow colleagues caused mixed responses. Many colleagues and medical students have mood disorders, and they came out to her after she came out. Most colleagues thought it was a good idea to go public and most had no idea she had this illness. Some withdrew and they have an ongoing discomfort. She even received a letter of support from a senator. She has received at least 25,000 letters so far from people. "Most people have been remarkably supportive." "Some letters, actually many letters, have been vicious, saying, for example, that because bipolar illness is genetic, it is a blessing that I have not had children, that I spared the world of yet another destructive psychotic." "Others peoples' letters were, not surprisingly, overtly psychotic, many staggeringly so. And I have had hundreds of letters from Christian right, berating me for having abandoned my faith, which I had not been aware I had done, and making it clear that I deserve to rot in hell for all eternity because I had not accepted the pre-

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enlightenment views of madness of demons and possessions.” “Other letters were simply anti-science, anti-medicine and very strong anti-psychiatry movement in this country, and often very mean spirited and highly personal.”

“All things considered, though, I am much more able to say what I really feel now.” “I’m much more myself now.” “For every discomfort about the loss of privacy, for every fear of a personal or professional reprisal, there is tremendous relief in the honesty. For the most part, people have been infinitely more understanding than I would have imagined. It is true that a few of my colleagues have quite publicly questioned my judgment for writing about my illness, and yet others have questioned my professional ethics for not having written about it earlier.”

“Certainly the entire process has drawn my family more tightly together. We began talking about an illness that is rampant in my family, that for so many years and for so long we skirted around. It has become a part of our casual conversation, a much more natural part of our lives.” She goes on to say a few months after she came out, her then-11-year-old niece wrote a project for school about manic-depressive illness in her family.

### **Part Two: The Q&A**

Q: A man says his illness is now public information and he has lost his licence to practice medicine and feels he is being discriminated against.

A: “Without making too much of an individual case of this...” “Does anyone have a right to practice? Of course not. The health of patients and the safety of patients is always primary and always has to be dominant.” “Suicide is five times more common in women doctors as in women in the general public.” “What we routinely tell the medical students at Hopkins is, you’re not responsible for getting depression...You are responsible as a young doctor to get treated and you’re responsible to keep a wing out for your colleagues and to look out for impairment and to (missing word) in the best interest of the doctors.” “The single, easiest way to make you manic is to stay up all night...And when are people most likely who have the genetic predisposition to bipolar illness who haven’t gotten manic already, when are they most likely to do it?...Clinical rotations when they stay up all night.” So residents with mood disorders at Johns Hopkins are told not to stay up all night in Emergency, but they have to make up the work elsewhere. She tells of a resident recently who tried to quit studying Medicine when he was depressed, but, as with others in this position, he was encouraged to get well and then decide whether or not he wanted to quit.

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Q: Do you have a trick to coping with stress and staying well?

A: She says she is lucky in that she responds well to her medicine. She says stress is not a trigger for her, as she does well with stress. Sleep, however, is a big trigger for her.

Q: A man says his daughter hates lithium.

A: Dr. Jamison says all psychiatric drugs have problem side effects. Lithium is not patented so there is no profit margin on lithium. However, "Lithium remains the gold standard for the treatment of bipolar illness." "It is demonstrably an anti-suicide drug." "There is a lot of evidence it is growing good things in your brain."

Q: What is the direction of DNA research?

A: "Bipolar illness is a very genetic illness." She says there are a lot of labs around the world looking for the genes responsible for bipolar. Finding the genes would mean, "You could diagnose people earlier and more accurately, develop much more specific treatments, and develop things that might actually work fundamentally to prevent the illness from ever happening." "The combined use of medication and psychotherapy is much more effective than taking medication alone."

Q: Someone asks about the "apocalyptic thing about Tom Cruise?"

A: "I need my garlic and my cross when you mention Tom Cruise."

Q: Someone asked about a new Virginia law to force medication on psychiatric patients.

A: She says the law is only for very severe cases of mental illness and implies this is a good law.

Q: What else do you want to be remembered by other than your work? What are some things that you like to do?

A: "I like to walk and read." "I love going to the zoo." "I spend a lot of time at the Smithsonian."

Q: Not enough research goes into personality disorders.

A: Dr. Jamison says any research on the brain, such as that done by NARSAD, will help all

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mental illness disorders, including personality disorders.

Q: Someone asks her opinion about the law that just passed in the House of Representatives.

A: She says they have tried to pass this Mental Health Parity Act for many, many years. But now it has passed by a large margin with 120 votes and will help to lessen discrimination against the mentally ill. She is very pleased about this. “So things are changing.”

Q: Someone asks if there is additional stigma in Asian American community.

A: Dr. Jamison says, yes, there are clearly cultural differences in stigma, with worse stigma with Asian Americans.

Q: How do you help a person who clearly has bipolar illness but refuses to accept diagnosis or treatment?

A: “Two major clinical practical problems in treating mood disorders, and in particular bipolar disorder, but mood disorders in general are, one, the issue of will people stay in treatment, assuming good treatment. There is a whole other issue of bad medical care.” She says that under the age of 30, people are much less likely to stay on their medications. “The other one is, how do you...convince somebody that they’re sick? It’s a hard sell. It flies in the face of reality. Is this what involuntary commitment is all about?...Often it doesn’t work...When they’re feeling well and they have good insight into the fact that they have mental illness and it has to be treated, get them to draw up with their doctors an arrangement or an agreement that says that this is what I want done if I lose my insight, if I get mentally ill. I know DBSA has one because I used their form in my book. They had lawyers draw up these kinds of agreements...So you can say, I don’t want this kind of medication and I do want this treatment. For example, I’ve said if I get sick, I want to go to Hopkins, I want the following doctor to treat me, I want ECT (or shock treatment), I want to be hospitalized against my will, and I want this no matter what I say at the time – I give you my permission to do these things.” “When you have an illness that has the capacity to erode reason, you want people [to be] rational.”

Q: Someone asks about the relationship between bipolar being genetic and its treatability.

A: “Even if it’s genetic, I think it’s important to realize that it’s treatable.”

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Q: (inaudible).

A: “I spend a lot of time speaking to students who are relatively new into their illnesses. I try to tell them there is a huge investment you have to make in the early years of your illness because what we know about the brain more than almost anything is that the longer it is stable, the longer it stays stable. The brain is like a pond. It’s like an ecosystem. You want to get the ideal ecosystem and then you don’t want to disturb it very much. So you don’t want to be messing around with drugs. You don’t want to be messing around with sleep. You don’t want to be messing around with alcohol. You want to really create a stable environment. That period of time is just incredibly, horribly difficult. But once you’ve figured that out – the combination of medications, psychotherapy, lifestyle routine, and so forth – then you have a real shot at having a stable life. It’s really very frustrating, because that initial period has a level of difficulty.” “Different professions give you different latitudes. One of the disadvantages [of an academic profession] is the huge amount of pressure. The advantage is that you have a lot of latitude.” “I certainly put in that initial time of great instability. There is no easy way around that.”

Q: How does the brain mutate and change over the years?

A: “I don’t know that anybody really knows how the brain mutates and changes over the years. I would say at the most simplistic level is that if you took a scan of your brain on one manic episode, you would prefer to have that brain than the brain on five or six or seven manic episodes. It’s one of the most compelling arguments for staying on your medications and being aggressively treated. You can’t keep having heart attacks. You can’t keep having strokes. You can’t keep having depression and you can’t keep having manias, without paying a biologic cost.”

Q: Is there any research or author she knows about on the subject of the overlap of PTSD and bipolar.

A: She says with so many people coming back from the war, the body of work in this area is growing. She talks about Robert Post’s discussion on the kindling theory in bipolar, and that she thinks there is some work where this is applied to PTSD as well.

Q: Someone asks how to get her unstable son into treatment.

A: She says NAMI has information on that. She says she will conclude Q&A with this subject, about bipolar in children. She says bipolar is similar in adolescent-onset as with adult-onset, “in terms of symptom presentation, in terms of treatment response, in terms of

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the natural course of the illness (in other words, how it unfolds over time), prognosis, and so forth. The younger the age of onset, the more complicated it gets. Certainly bipolar illness exists in the young, and certainly in the last 10 years there has been an incredible amount of research into that field. I think at the end of the day that is going to be really helpful. At the moment, it is sort of a confusing literature. Part of that is because the presentation of bipolar illness in the very young is quite different from the presentation of bipolar illness in the older and adolescents. In common, you see the volatility, the impulsiveness and the rage. Those things you can see in adults as well, but those are perhaps more characteristic of those who are young. We know that the very young onset by in large has a worse course and it's a more difficult illness, but the treatments again are much more specific and much better studied." "For a long time people didn't even think that kids could get depressed [even if they were psychotically depressed]." She says now we've gotten to a point where people are admitting mental illness is possible in the young, but we haven't gotten to a stage yet of knowing how to put children on the right medication. "The future looks good. Thank you."

Applause!!!!

### **Part 3: Impact and Impressions**

So that was the objective reporting on the talk, based on my tape recording of the night. Below are my own impressions of Dr. Jamison and how her talk affected me.

One of the things I like the most about Dr. Jamison is that she is strong and not afraid to take a stance, as you can see from the transcript of her talk. She does this without raising her voice or getting visibly rattled or swearing, which is something I admire. Rather, she is articulate, tranquil and humourous, and she is able to gently massage the English language poetically to make everything she stands for sound ideal.

As you can see in Dr. Jamison's biography, she writes even better. In her biography, I was completely engrossed in how she described bipolar illness, particularly how she was able to capture the madness. Psychosis is difficult to describe for it is otherworldly, but having been there myself, I think she did a fabulous job and I am grateful for that work she has done for those of us who have a difficult time putting it to words. I read her biography for the first time in 1999, and it was the first time anyone resonated with that part of me.

Dr. Jamison is very aware of the current problems for people with mental illness – problems with legislation, public opinion (stigma), therapies, scientific database,

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medication side effects and so forth. However, she has seen the direction of change in these areas and is therefore hopeful that these areas will continue to change for the better. Having been in the system myself for 25 years now, I share her optimism for the same reason.

Having lived a long time in medication noncompliance and denying her illness herself, Dr. Jamison is also empathetic towards people who have mental illness and is therefore an excellent advocate for many of us. Sometimes an ex-smoker is the worst advocate for a smoker to quit smoking, for the ex-smoker is so hell-bent on forcing their path on others. Similarly, sometimes the recovering psychiatric patient is the worst advocate for a struggling psychiatric patient, for the recovering patient is so hell-bent on forcing their path on others. I happen to share Dr. Jamison's path of recovery within the psychiatric system, though, so I am able to enjoy her advocacy efforts. Mind you, at first I had a path of destruction caused by the psychiatric system itself. But again, perhaps because it was hell with my first psychiatrist, I am able to see the progress and appreciate the psychiatric system now. Sort of like how I relish in the technology we have now because I grew up without it.

Dr. Jamison is also a responsible person because she has the foresight (through experience) to know to develop a plan of advanced directives. She also shows a lot of guts by saying ECT can be given if needed. I have advanced directives too, and will improve upon my plan this year.

When Dr. Jamison spoke about the difficulties in going public and the freedom she experienced because of this honesty, I could totally relate to that. I went public with my name for the court cases I did to prosecute my parents and first psychiatrist for many reasons, and one of them was, like Dr. Jamison, in an effort to promote public awareness. If my name were not public, the crimes committed could not have been made public. So I took off the publication ban on my name. And it went national. And everyone found out. And I felt so vulnerable and humiliated and raped of my inner self. And hurtful things were said, like with Dr. Jamison. But, as with Dr. Jamison, almost everyone was supportive beyond my expectations. Dr. Jamison says that having bipolar illness for so many years makes dealing with going public easy in comparison. For me, I said at the time of the court cases that having lived through all those years of abuse made coming out easy in comparison. Then I got hit with one psychotic episode after another. So perhaps I could say that because of the psychotic episodes, I now I have more strength to take the next step in going public. You know, I do want to write my book about madness and the court cases. To publish, I do have to come out with my name again. The internet is a safe haven for anonymity for those of us with mental illness. But who does the secrecy protect?

Cristina Romero-Sierra, Speaker Attendee

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What does the secrecy stand for? My phone number is unpublished, so no one can find me based on my name and city. There is not enough information here for people to steal money from me or my identity. I don't want that hurdle of lifting the secrecy to be looming over me anymore. So in honour of Dr. Jamison's talk, in honour of admitting the possibility that one day I may go public again by writing a book, and with the expectation that the world will accept another real person with mental illness, I want to add my name to the list of people who have come out about their mental illness. My name is Cristina Romero-Sierra. I may never publish a book, but the owner of the Mood Garden forum is letting me publish there, along with other people with mental illness, and I now do that with my real name. I am grateful for this opportunity.

Thank you for the talk and the book, Dr. Jamison. Yes, things are changing. Thank you for showing us your torch of hope and courage.