

Family Stressor: Mental Illness

*A discussion of major mental illness
its affect on families, and how families are
improving the mental health care system*

NAMI Finger-Lakes
namifl@lightlink.com
www.namifingerlakes.org

Why Should You Care?

- Some of your friends & relatives will develop a major mental illness (>7% of population)
- You know families affected by mental illness (20% of families)
- You will deal with it professionally (especially social work & medicine)

Why Should You Have Hope?

- Mental illnesses are treatable brain disorders
- Modern treatments allow many mentally ill adults to lead good lives
- Family-based organizations are lobbying hard to improve treatment and support systems.

My Qualifications:

- Multiple relatives & friends with schizophrenia and bipolar disorder
- Personal experience with family crisis & hospitalization.
- Member of NAMI (National Alliance on Mental Illness)
- Member of Ithaca NAMI affiliate (NAMI-Finger Lakes)

Today's Agenda

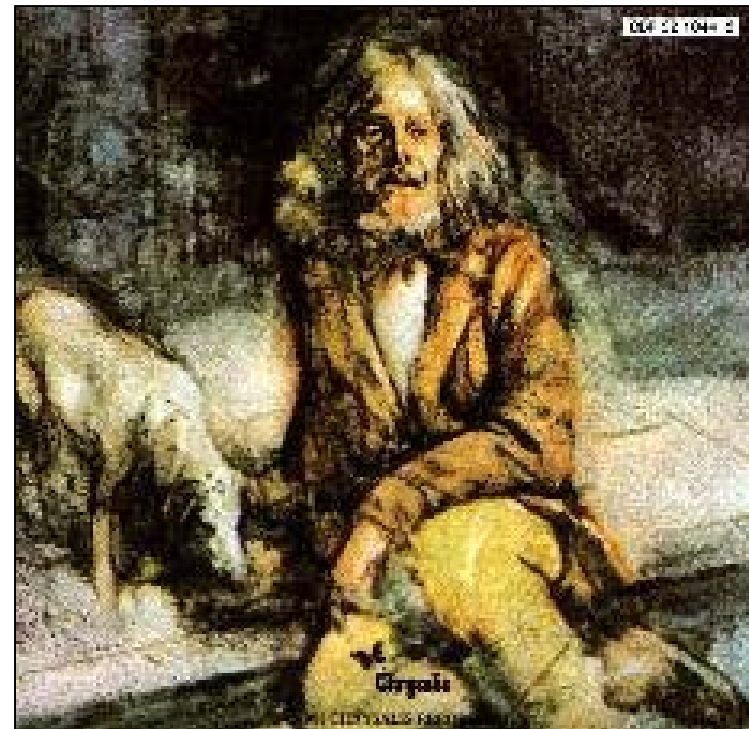
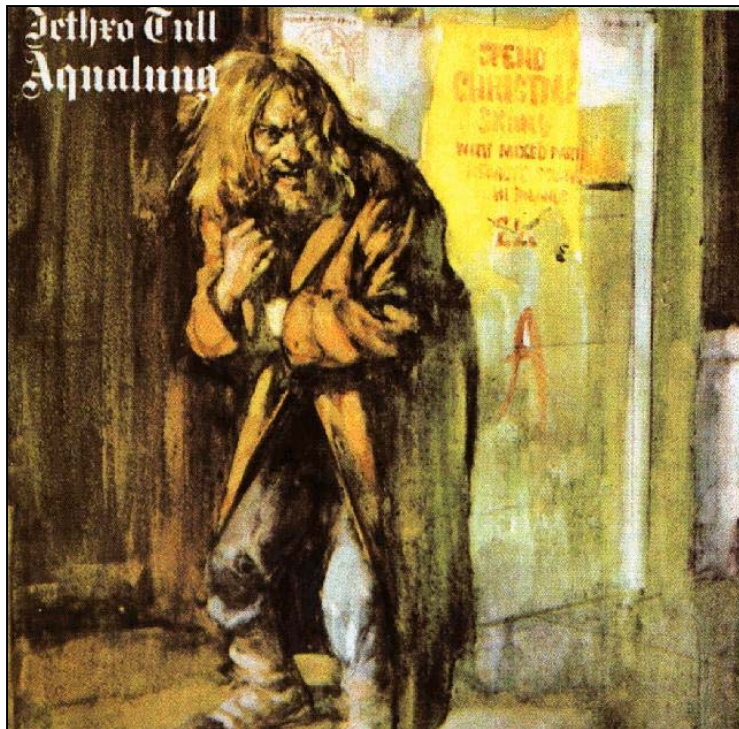
- What is a major mental illness - and how is it diagnosed & treated?
- How does mental illness impact families?
- How are families forcing change on the mental health care system.
- And could you do me a favor.....?

What is Major Mental Illness?

- Lifelong biologically-based brain disorders that affect thinking & emotions
- Typically develops in teens to 20's - the “big three” are:
 - Major Depression (5% of population)
 - Manic Depression (1.2% of population)
 - Schizophrenia (1.1% of population)
- **Occurs in all social classes & societies worldwide**
- Leading Cause of Disability in North America & Europe
- Major Contributor to Alcoholism/Drug Abuse, Suicide

Who Are The Mentally Ill?

(the myth)



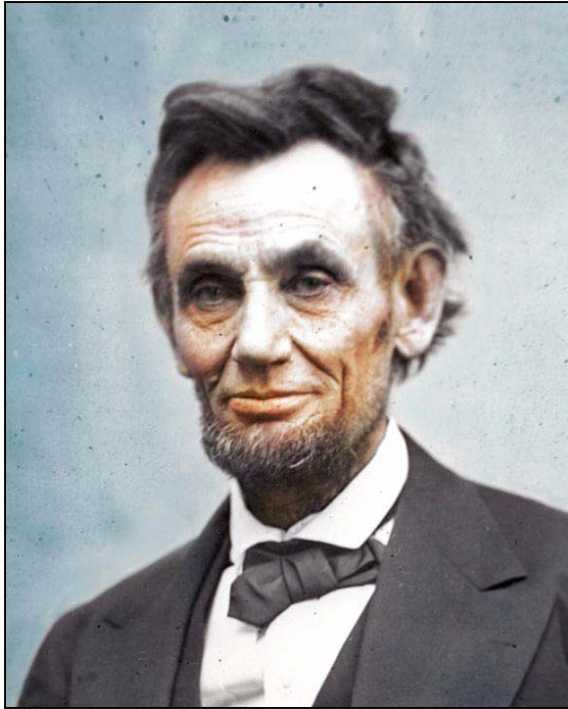
Who Are The Mentally Ill?

(The reality)



Cornell Presentation, April 26, 2006

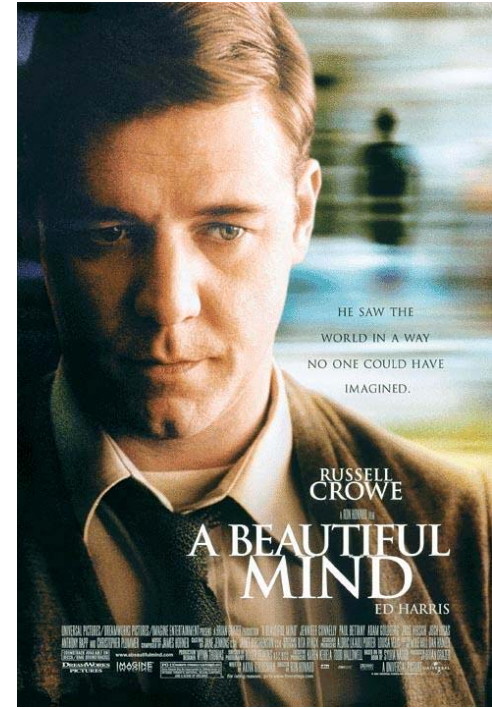
An Overview of the “Big Three” *(and some famous people)*



Abraham Lincoln
(major depression)



Carrie Fisher
(bipolar disorder)



John Nash
(Schizophrenia)

Major Depression

(a mood disorder - you go down & stay down)

- Symptoms:
 - Early Morning Wakening
 - Listlessness
 - Extreme Fatigue (worst time is morning)
 - Feelings of sadness, cheerlessness, indecisiveness
- Most episodes last at least one year

Major Depression

(the internal experience)



“I am now the most miserable man living. If what I feel were equally distributed to the whole human family, there would not be one cheerful face on the earth”.

“Whether I shall ever be better I can not tell; I awfully forebode I shall not. To remain as I am is impossible; I must die or be better, it appears to me”.

Bipolar Disorder/Manic Depression

(a mood disorder - a pendulum)

- **Cycle between mania & depression**
 - Cycles can range from days to years
 - Often misdiagnosed as depression
- **Mania means**
 - boundless energy, little need for sleep, hypersexuality, extreme agitation
 - common to get into financial/legal problems
 - very hard on marriages & friendships

Bipolar Disorder

(the internal experience)

- **Depression:** *“I doubt completely my ability to do anything well. It seems as though my mind has slowed down and burned out to the point of being virtually useless.... [I am] haunt[ed]... with the total, the desperate hopelessness of it all....”*
- **Mania:** *“The fast ideas become too fast and there are far too many... overwhelming confusion replaces clarity... you stop keeping up with it—memory goes. Infectious humor ceases to amuse. Your friends become frightened.... everything is now against the grain... you are irritable, angry, frightened, uncontrollable, and trapped.”*

Schizophrenia

(affects reasoning, thinking, perceptions)

- Brain doesn't correctly process reality
 - Hallucinations (hears voices, sees things)
 - Delusions (false beliefs)
 - Strange actions, rituals, swearing/shouting
 - Lack of emotional response
- The most debilitating mental illness
 - Often can't work or maintain relationships

Schizophrenia

(the internal experience)

- *Unrecognizable voices invaded my ears; transmitters had been planted in the ceiling; everyone on the Hall spoke about me; my behavior was watched and discussed by the staff...killers hid behind closed doors and waited until night to sneak into my room.*
- *I hear this voice sometimes...sometimes the voice booms in my ears, other times it sounds like a song, a melody, but the lyrics, even though the singing is sweet, are filled with criticism and attack. The verbal abuse never lets up - it goes on and on for hours.*
- A Schizophrenia “Simulation” can be viewed/heard at:
<http://www.npr.org/programs/atc/features/2002/aug/schizophrenia/>
(requires Real Player)

What Causes Mental Illnesses?

- The “Double-Hit” Theory
 - A genetic tendency to developing illness
 - Some environmental factor that triggers it
 - Probably many factors that could cause it.
- Identical Twin Studies support theory
 - Schizophrenia (35-50% risk)
 - Major Depression (59% risk)
 - Bipolar (74-80% risk)
- *No one truly knows how or why illnesses develop*

Diagnosis & Treatments

- Mental Illnesses are diagnosed by observation (no blood or imaging tests exist)
 - DSRM-IV has standard “recipes” for diagnosis
 - Diagnosis only good as info provided to MD
- Mental Illnesses are treatable
 - Meds, Therapy, Self-Care can often control symptoms
 - Many people successfully manage their illnesses
- *A good diagnosis is critical*
 - wrong diagnosis = wrong treatment = lost years
- *Crucial to involve family in diagnosis/treatment!*

So Why Do People Continue to Have Problems?

- Medications are “trial and error”
 - Try it and see what happens
 - Can take 4-6 weeks to see if it works
 - Can take months/years to find an effective medication
- People quit meds because of Side-Effects
 - Weight gain + greater risk of Type-II Diabetes
 - Can affect digestion, sleep patterns, lowers sex drive
 - More serious side effects possible, though rare

People Are Cured After Taking Their Meds - Right?

- Mental Illnesses aren't "cured" by meds - the *meds control symptoms*
- Stopping Meds = Risk of Relapse (very common)
- Developing mental illness = loss of self-esteem, confidence, and family support (meds can't control this)
- Recovery involves meds, good treatments, self-care, and support systems (similar to diabetes...)

The Treatment System

- Most Insurance doesn't cover Mental Illness
 - Many plans are a “few weeks & out”
- Hospitals under cost pressure
 - Can take months to stabilize
 - Dump ‘em out as quickly as possible
- De-Institutionalization Didn't Work
- Jails are now the largest mental health system in the US

Dual Diagnosis Complicates Recovery

- Common to “self-medicate” (drugs/alcohol/tobacco)
- 29% of Mentally Ill addicted to drugs/alcohol
- 37% of alcohol abusers, 53% of drug users have one major mental illness
- Must integrate mental health & drug recovery teams!

The Best Treatment System Is:

- The best medications & psychiatric treatment
- Strong continuing support programs (especially housing)
- Transitional Programs to ease people back into the workforce
- Kindness and Hope are just as important as Science (ex: Colorado Mental Health HMO & NY PACT program)

A Commercial Break from NAMI-Finger Lakes

- It sounds grim, doesn't it?
- However, things are improving!
- Meds & treatments have dramatically improved in last 20 years,
- Families are pressuring government to improve treatments and care systems.
- We are getting there!

How Does Mental Illness Affect the Family?

- Emotionally
- Financially
- Spiritually
- Attitudes Towards Government

The Stages of Emotional Response

- #1: Dealing with Catastrophic Events
 - Crisis/Chaos/Shock/Denial
 - Hoping Against Hope
- #2: Learning To Cope
 - Anger/Guilt/Resentment
 - Grief & Recognition
- #3: Moving Into Advocacy
 - Understanding & Acceptance
 - Advocacy/Action (Charge!)
- *You repeat The Stages with Each New Crisis*

Other Emotional Issues

- Stigma
 - Not discussed in community/family/church
 - Mentally Ill relatives “hidden” in family
 - Silence kept even after death
 - Major issue with many immigrant groups - most recently Asians
- Inheriting a tendency towards mental illness
 - Mental illness runs in families
 - Will my kids/grandkids become ill?

Financial Issues

- Paying for meds & treatments
 - Many families exhaust financial resources
 - Can damage marriages & sibling relationships
- Housing
 - Living at home often impossible
 - But where can they live? Homelessness is common
- How long do you support them?

Spirituality

- Why us - why my relative?
- Some religious groups don't believe in taking medicines
- Some religious groups don't believe in mental illness
- Often a blame game "you didn't raise them right - you were sinful"

Further Observations (Support Group Experience)

- Stigma
 - mental illness is often considered “shameful”
 - often little support or empathy within extended family
- Gender Roles
 - Women are the most involved caregivers
 - They follow Winston Churchill’s advice:
“Never give in. Never give in. Never, Never, Never, Never”
- Anxiety
 - When will next crisis hit?
 - What happens after I’m gone?

Another Commercial Break from NAMI-Finger Lakes

- Feeling a bit down after hearing all this?
- Actually things are getting better - and families/students are driving change!
 - NAMI (National Alliance on Mental Illness)
 - Timothy's Law (Insurance Parity in New York State)
 - Ophelia's Place (Support Organization for Eating Disorders)
 - Cornell "Minds Matter" (student-run mental health/advocacy organization)

Other Observations + Good Reading

- Excellent Books:
 - “Surviving Schizophrenia” and “Surviving Manic Depression” - Torrey
 - Overcoming Depression - Papolos
 - “I Am Not Sick and I Don’t Need Help” - Amador & Johanson
 - The Surgeon General’s Report on Mental Health (Dr. David Satcher)
- Famous people are “coming out”
 - Celebrities (Carrie Fisher, Linda Hamilton)
 - Politicians (Prime Minister of Norway)

Could You Do Me A Favor?

- You know families struggling with mental illness
- Tell them about NAMI (National Alliance on Mental Illness) and Family-to-Family
 - **www.nami.org**
 - >1000 affiliates in US, Canada and Mexico
 - In Ithaca ==> **www.namifingerlakes.org**
 - We Are Families Helping Families (and anyone else who would like our help!)