



MINDS ON THE EDGE: Facing Mental Illness

Viewing Guide

Introduction

The objective of a Fred Friendly Seminar is to open minds to the complexity and ambiguity of issues facing contemporary society. The Seminars begin by painting “little pictures” – dilemmas or conflicts such as almost any viewer would confront in their lives – that lead into a compelling exploration of large ethical, emotional, legal, and public policy questions that are challenging us as individuals and as a society.

The Seminars bring together a panel of informed participants, carefully chosen to bring a variety of professional expertise as well as personal experience to the discussion. As they wrestle with the issues presented, they are encouraged not just to say what they think about an issue, but to say what they would do in difficult decision-making situations in which there may be no “right” or “final” answer.

As a viewer, you are asked to do the same. Try to stand not only in your own shoes, but in the shoes of the characters in the hypothetical scenario that is about to unfold. Draw on your values and your real world experience to imagine what you would do if confronted by these issues. As the story unfolds, reflect on whether your views remain the same or evolve as more information is presented. And consider if there is more information that you would like to learn in order to make the best decisions.

As our hypothetical scenario begins, moderator Frank Sesno describes a professor who is worried about one of his students named Olivia. She is a gifted young woman who lately seems quite agitated and disheveled. Those who care about Olivia struggle to make sense of what is happening and how they should respond as her behavior gets increasingly troubling. Meanwhile, in another part of town, a man named James experiences a return of the inner voices that have tormented him in the past. As Olivia, James, and those around them face the challenge of severe mental illness, our panel of physicians, family members, attorneys and judges, scientists and government leaders – some of whom themselves live with mental illness – describe what they might experience, obstacles they might encounter, issues that might arise, and alternatives that might help.

Additional information is available on the web at www.mindsontheedge.org.

How to use this guide to facilitate a group discussion

A group discussion can be structured in a variety of ways depending on your audience, your objectives, and the time available. If you are hosting a large screening, consider breaking out into smaller groups for discussion.

The entire program of *MINDS ON THE EDGE* is 60 minutes in length, but it is divided on the DVD into 6 chapters of about 10 minutes each. Pre-screen the program to determine the best strategy for your group. Determine if you want to show the entire program or only selected chapters. If you show the entire program, you might pause for discussion after each chapter. Allow 10-15 minutes of discussion for each chapter.

Successful communication provides for an open interchange of ideas. Provide a safe learning environment and encourage participants to share their questions or ideas. Understand that strong feelings may be evoked by the dialogue, but maintain a supportive tone. Identify ways to be inclusive and utilize existing talents in the group. Don't feel that you have to know all the answers. Remember that the session will provide a learning experience for the participants as well as the facilitator.

Recommendations for leading an effective discussion:

- Set the tone for the event by playing the program introduction to give your groups a sense of the scope of the program and the experience ahead.
- Have participants introduce themselves.
- Emphasize to the group that this should be an open discussion. That there are often no "right" answers to these challenging questions.
- Each chapter is divided into several segments. The viewing guide provides a brief synopsis of each segment to help you recall the story as it unfolds. These can be read to your group to set up the next set of questions, or simply refer to the story to frame the questions you are about to ask.
- Consider the listed discussion questions as suggestions. Feel free to alter them or create new ones, especially if you know enough about the participants to select issues that are meaningful to them. Listen carefully to the answers and adjust your next questions accordingly.
- Ask open-ended questions to guide the discussion. Don't try to control it.
- Encourage debate and differences of opinion by playing devil's advocate at times.
- Have participants explain how they reached their conclusions.
- Encourage members of the group to interact with one another, discussing the ideas expressed and keeping criticism constructive.

Sample questions to stimulate discussion:

Clarifying Questions

- *"I'm not sure I'm with you. Do you mean _____?"*
- *"What is the difference between what is happening now and what you would like to see happen?"*
- *"Let me see if I understand you. You _____"*
- *"For the benefit of everyone, can you clarify _____"*

Probing

- *"Can you expand on that?"*
- *"What do others think?"*

Open-Ended Questions

- *"What is your understanding of the problem?"*
- *"What are the issues that concern you?"*
- *"What would be the best possible course of action?"*

Deflecting

- *"That's an interesting point. What is your/the group's analysis of the problem?"*

Consensus

- *"Are we in agreement regarding _____?"*
- *"Do you wish to reconsider given what we have just heard?"*
- *"What does the group think of the idea?"*

Chapters and Questions

For sections within each chapter, bulleted questions are provided to guide group discussions.

Chapter I – Worried About Olivia

A. As our story begins, a Commonwealth University professor witnesses disturbing changes in his student Olivia. She is speaking very rapidly. She appears disheveled. Her last paper was covered in notes that didn't make sense. The professor fears that Olivia is becoming ill and may be experiencing a manic episode. Supreme Court Justice Stephen Breyer, playing the role of the professor, struggles with how to approach the problem. He turns to panelist Dr. Eric Kandel for advice.

- Have you ever witnessed troubling changes in behavior in a student, employee, friend or family member? Did you struggle to understand what was happening and what, if anything, should be done about it?
- If so, what sources of advice and support were available during that time, when the possibility of illness first revealed itself?
- What advice, resources or support did you wish had been available? (What was the best advice you received at the time? The worst?)

B. Dr. Eric Kandel is a Nobel Prize-winning scientist who studies the brain. He too worries that Olivia is experiencing a manic episode, and he advises Justice Breyer to speak with Olivia directly and show empathy with her. Dr. Tracey Skale, a psychiatrist, agrees that “having that empathy and initial support is a huge factor.”

- Have you ever approached a student, employee, friend or family member to talk about changed behavior that might be caused by mental illness? Or, have you ever been approached by someone seeking to talk about your own difficulties?
- Do you agree that showing empathy when a person is agitated is especially important? Did you express – or receive – empathy in the exchanges you experienced? If so, how was empathy demonstrated? If not, what words, actions, or omissions made the lack of empathy apparent?
- What do you believe is most important to say, or to hear, in an exchange like this?
- Is empathy and showing support the right approach? Is “taking charge” or “setting boundaries” the right approach?

C. Panelist Fred Frese, a psychologist who himself has a diagnosis of schizophrenia, role-plays the character of Olivia drawing on his personal and professional understanding of the illness. As Olivia, he asserts “there's nothing wrong with me. . . . I'm just working on something.”

Ultimately, Justice Breyer as the professor admits that his effort to get Olivia to speak to a counselor has not gone well. Fred Frese has resisted the suggestion, asking, “Do you know this counselor?” He wonders if a counselor could be trusted.

- Does the fact that that Olivia resists going to the counselor, and insists that nothing is wrong, mean that the exchange was a failure, a waste of time? What value can an exchange like this have, even if it seems “unsuccessful”? Any?
- In your own experiences, is it always easy to admit when you need help? Should some resistance – perhaps a great deal of resistance – be expected in a situation like this? What might help overcome resistance, in your experience? How might showing empathy and compassion positively affect Olivia?
- In a real-life situation, how do you think someone can best prepare for this kind of exchange? What information should be at hand, in what form? How does one find an appropriate counselor?

D. The professor then remembers that he met Olivia’s parents at the last Parents’ Day Weekend. When asked whether, as the professor, he would call Olivia’s parents to discuss her behavior, Justice Breyer says, “Absolutely.” Panelist Susan Stefan suggests that the professor’s phone call might violate FERPA, a law that protects the privacy of student records.

- If you were in the position of the professor, would you call Olivia’s parents? If you were a college student, would you want your professor to call your parents to discuss your behavior? If you were Olivia’s parents, would you want that call from the professor?
- Olivia is an adult, over 18 years old. Should that make a difference?
- Even if the law does not apply in this case, should the professor consider the student’s privacy and autonomy before calling?
- Should the professor tell Olivia that he is calling her parents beforehand? Afterward? What if she specifically asks him not to?
- If you were a University administrator, would you want the professor to make that call?

Chapter II – Taking Olivia to the Emergency Room

A. After the professor’s call, and their own inability to reach Olivia on the phone, her parents decide to drive to the campus. When they arrive, the parents discover that Olivia has not been to her dorm room for several days. Eventually, the parents find her wandering alone in a park, walking in circles and muttering. Pete Earley, a journalist whose son has bipolar disorder, role-plays Olivia’s father. He asks, “Tell me what you’re thinking.” Avel Gordly, whose son has schizophrenia, describes how she would behave if she were Olivia’s mother, saying, “I throw my arms around her, and I hug her.” Dr. Frese, still assuming the role of Olivia, describes a plan to visit a \$700-a-day spa in order to “solve all the problems I’ve worked on.” But Olivia’s parents believe she is seriously ill, and they want to take her to an emergency room.

- What would you say or do if you were Olivia’s parent at that moment?
- If you were Olivia, what would you hope your parents would say or do?

- Have you or someone you know ever been in an experience similar to the one faced by Olivia, or Olivia’s parents, in the park? What happened? What words or actions at that moment were the most helpful? The least helpful?
- Should Pete “play along” with Olivia’s plan while trying to get her to an emergency room.

B. When Olivia’s parents get her to the emergency room, Dr. Thomas Simpatico, in the role of the emergency room physician, spends some time with Olivia, and says, “I would not feel comfortable having Olivia simply leave the emergency department.” However, Pete Earley and several other panelists say that if Olivia refuses to stay in the hospital, she will be released, despite signs of severe mental illness. Judge Steven Leifman, a federal judge in Miami, explains that under the “imminent danger” standard Olivia will be released because “She’s not an imminent threat to herself or anyone else.” Estelle Richman, who is Secretary of Public Welfare in Pennsylvania, observes that if Olivia becomes agitated, she will run out the door, “and no one’s going to stop her.”

- Despite her delusions, Olivia does not pose an imminent threat of harm to herself or others. As an adult, should she be allowed to leave the hospital if she so chooses? If not, what should the legal standard be for keeping someone in the hospital against their will?
- Have you or someone you know ever been in the situation of Olivia in the emergency room? Of Olivia’s parents? Of a physician or other provider at the ER? What standard was used in the situation you experienced? What standard do you think should have been used?

C. As Olivia walks out of the ER despite her parents’ pleading, a nurse comes up to the parents and says: “If you want to get her admitted, tell them that she threatened to kill you. That’ll get her in here.” Avel Gordly says she would lie to get her daughter help. The choices at the ER seem to be between completely following Olivia’s wishes to walk out, and completely ignoring them by keeping her in the hospital against her will.

- What would you do if you were Olivia’s mother?
- If Olivia’s mother lies about her at the ER, how might Olivia react at the time? How might she feel about it later?
- Can you imagine any other options that might be better than either watching Olivia leave or keeping her against her will?
- What might you try if you were a provider at the ER?
- If community-based alternatives to hospitalization were available, if you were Olivia do you think you would feel more comfortable going there on a voluntary basis?

Chapter III – James Gets Arrested

A. As Olivia walks out the door, Dr. Tracey Skale observes, “What a heart wrenching story. Because I’m fast forwarding 20 years from now. And 20-year-old Olivia is now 40-year-old Olivia. And she’s sitting in front of me lamenting the last 20 years she has lost.” With that, the moderator introduces a new character in the hypothetical. James is 32 years old and has heard voices on and off for years. The voices say that he is a

piece of garbage, and that if he gets close to other people, he will contaminate their souls. When he's heard these voices in the past, his mother was able to support him. But now his mother has died, and the voices have returned. Schizophrenia can have positive symptoms like delusions, negative symptoms, and cognitive symptoms. Elyn Saks, who developed schizophrenia in her teens, went on to become a law professor and she specializes in mental health law. She says, "The best way to describe having a psychotic episode is like a waking nightmare."

- Does this description of schizophrenia match your own understanding of the disease? Does it include things you didn't know about?
- Is there anything you would add to the description, based on your own knowledge or experience?
- What might you find reassuring if you were in such a state?
- Do you think this description of schizophrenia is commonly understood by your friends or colleagues? What misperceptions have you heard? What are the possible consequences of such misperceptions?
- Many people diagnosed with schizophrenia recover and live full lives in the community. Did you know that?

B. Feeling alone and scared, James stays in his apartment and loses his job. But James realizes he needs help, and goes to an emergency room. Unlike Olivia, James is eager to receive help from the hospital, but the ER staff refers James to an outpatient clinic with an appointment three weeks later. Lauren Spiro, who advocates for peer support programs, explains, "James is absolutely in crisis...If I'm James...I need a safe place." Left to fend for himself, James becomes disoriented and winds up being arrested for public urination. Instead of being in the hospital where he sought help, James ends up in jail. Now, the time and resources of a police officer, a judge, and the rest of the criminal justice system will be used to respond to James' misdemeanor. In fact, Judge Leifman observes, "Judges are much more likely to see consumers with mental illness than [are] psychiatrists."

- Have you or someone you know been in the position of James or someone who cares about James? What did you experience?
- If sending James off with an appointment in three weeks was a mistake, what should this overcrowded, overwhelmed ER have done instead? Can you think of other options?
- If James had been referred to a peer support group, do you think he would have gone? What help might he have gotten there?
- Is this the best use of resources to respond to James' problem? Might a different, better response actually cost the community less instead of more?

C. Sadly, panelists offer two likely visions of James' future at this point: One, that he will drift into homelessness, or two, that he will be trapped for an extended period of time in the criminal justice system because, as Judge Leifman says, "we don't know what to do with him." For James and for those who care about him, these possibilities are tragic.

- Did you know about this cycle of mental illness and the criminal justice system.
- What priorities would you suggest to improve the system?

Chapter IV - Programs that Work

When the moderator asks the panelists whether James is simply a “lost cause,” panelists offer several examples of how James can be helped to live up to his potential.

A. Dr. Fred Frese argues for offering James a job, even if it begins a minimum wage for three hours a week. Elyn Saks calls the suggestion “fantastic” and argues that “we should be very supportive” of people with serious mental illness working and living up to their potential. As Elyn Saks observes, very often the opposite advice is given to those with serious mental illness: to withdraw from work or school, and to drastically revise downward what they can hope to achieve.

- Have you or someone you know had this experience of being discouraged from activities? Have you or someone you know had, instead, the experience of being encouraged to live up to one’s potential despite the challenge of mental illness?
- What was the experience, and what impact did it have?
- How can someone be encouraged to live up to his or her potential while accommodating for the challenges posed by serious mental illness?
- What changes, if any, would you recommend for someone returning to a job or to school?

B. Dr. Sam Tsemberis and Dr. Tracey Skale emphasize offering James choices and opportunities, “Either to work or to engage in treatment. Or to reconnect with family.” Offering someone a true choice, of course, means the person can choose an option you believe is not the best one – such as, perhaps, refusing treatment. Yet several panelists believe that offering James options and letting him choose is essential to helping him.

- Do you agree that someone diagnosed with mental illness should make their own choices? Why or why not?
- Are there any circumstances under which someone should lose their freedom of choice?
- What process should determine when someone loses their legal right to choose? What guidelines would you suggest?

C. When asked to offer examples of programs that work, panelists offer several. Judge Leifman describes Trauma Related Services, services for people who were sexually abused as children and suffer severe post-traumatic stress. Estelle Richman describes the need for programs to provide case management – one person to help someone like James make connections between different treatments and services. Pete Earley talks about Peer to Peer programs, where someone with mental illness can talk with someone else living with the same challenge. Avel Gordly describes Crisis Intervention Training, in which police officers are trained how to engage those with mental health problems to diffuse tense situations. In just about every case, panelists note both that the program described is helpful – and that it is not widely available.

- Have you ever heard of programs like these? Have you had experience with any programs like these? Do you think these programs would be helpful?

- Would you know how to find out if such a program is available to your community? What are the possibilities for learning more?
- If one or more of these programs is not available in your community – or if its availability is not well-known – what could you do to help make such a program available or better-known? What could your organization do? Your church, mosque, or synagogue?
- How might you or your organization advocate for programs like this in your community? What are the possibilities for drawing attention to these programs?

D. Returning to James' story we learn that he is, in fact, now living on the street. People in the area have called the mayor to complain. The mayor, played by bioethicist Art Caplan, wants to help James and those like him, but is facing the reality of severe budget cuts.

- Do you think our society can afford to provide more treatment and support for people with mental illness? If programs saved taxpayer money, should they be implemented? What if they cost more? Should cost be a primary determining factor?
- What would you say to the mayor?

Chapter V - Olivia and Civil Commitment

As James agrees to come in for treatment, we return to Olivia's story. Olivia's parents managed to get her to come home, and eventually received a diagnosis of her illness: bipolar disorder with psychotic features. One day the parents awake to find that Olivia is gone. They find her, sometime later, on a street corner, with a ripped blouse and a black eye, haranguing passers-by. The parents decide to seek civil commitment for their daughter. This might initially be hospitalization, but outpatient treatment is also an option.

A. Dr. Tracey Skale describes bipolar disorder thus: "A person with bipolar disorder will experience changes in mood. They might be manic . . . With high, high energy states. No need to sleep. . . Or they might have periods of extreme despair. Inter-episodically, they're neither manic nor depressed."

- Does this description of bipolar disorder match your own understanding of the disease? Does it include things you didn't know about?
- Do you think this description of bipolar disorder is commonly understood by your friends or colleagues? What misperceptions have you heard? What are the possible consequences of such misperceptions?

B. The parents seek civil commitment for Olivia. Under the law of the State of Commonwealth, Olivia is involuntarily committed – held in the hospital against her will – for up to 72 hours. Afterward, a court hearing is held to determine whether she meets the standard for continued involuntary treatment. At the hearing, Olivia will be represented by an attorney. Susan Stefan, playing the role of Olivia's attorney, explains that her job is to counsel Olivia but also to "represent what she wants" – which is to stay out of the hospital and that it is an essential part of our system that a person's freedom

can not be denied by another citizen, even if they are physicians, except in the more extreme situations. Dr. Frese, playing the role of Olivia, continues to speak about going to a particular spa; Olivia's hold on reality appears tenuous.

- Do you agree that Olivia's wishes should be represented at the hearing by her attorney? Is there a value served even when Olivia's perceptions seem nonsensical? What are the benefits to such a system? What are the costs?
- Have you or someone you know ever been in the situation of Olivia or of her parents?
- Was the person in Olivia's position shown "respect and dignity"? One way or the other, what were the consequences?

C. Under the law of the State of Commonwealth, Olivia's involuntary commitment will be continued only if the judge determines that she poses an imminent danger to herself or others. Justice Breyer observes that when the standard for involuntary commitment was too easily met, people were "warehoused" in institutions; when the standard is very difficult to meet, some people who need help will not receive it.

- What do you believe the standard should be in this situation?
- Is there any way to protect individuals' autonomy rights without involving the legal system?

D. Elyn Saks says, "We should . . . study how we could use less force. How we can . . . bring it about, so that people want treatment . . ." Estelle Richman observes, "Anytime you lock up someone against their will, you're going to almost always have a negative experience with that. You want people, if they need to be in the hospital, to want to be there."

- What could health care and social service providers, as well as friends and family members, do to lessen the need for forced commitment? Do any possibilities come to mind? What has been your experience?
- How could providers study how to use less force? Is less use of force safe for the public as well as the person with mental illness? How could this sort of study be encouraged?

Chapter VI - James and Mandated Treatment

While the judge at Olivia's hearing deliberates, the story returns to James. He is back out on the streets, hearing voices saying that he should die. At a street festival, surrounded by people, James feels the voices are closing in. He breaks a glass bottle to defend himself. Tragically, a shard of glass goes flying, cuts a little girl badly on the cheek, and blinds her in one eye. In the wake of this event, a bill called "Bethany's Law" is proposed. Modeled on New York's Kendra's Law, the bill would provide what is called "assisted outpatient therapy": people showing signs of serious mental illness can under certain circumstances be brought before a judge who can order hospitalization and mandatory outpatient treatment.

A. Dr. Fred Frese and Dr. Tracey Skale, among others, argue in favor of the bill, because, Dr. Frese says, “[When] individuals . . . are in psychosis, [they] are disabled with regard to their ability to make rational decisions as to what's best for them. . . . When you are in that state of total psychosis it is absolutely inhumane for society to ignore you . . .” Estelle Richman, Dr. Sam Tsemberis, and Susan Stefan, among others, argue against the bill, because, Richman says, “locking people up doesn't produce treatment.” Dr. Tsemberis observes that “James, in fact, had been seeking treatment. We don't need more laws for him to go to treatment . . .” He argues instead for “services in place that would create a more comprehensive safety net.”

- What other arguments would you make for or against Bethany's Law? What other factors would you consider?
- Should passage or application of the law first depend on whether appropriate mental health services exist in a community?
- Would you vote for or against the law?
- Whatever your position on Bethany's Law, what other changes are required to help prevent the tragedy that befell James and Bethany from happening again?
- What legislation would you propose?

B. As our story concludes, Dr. Eric Kandel is asked, “What gives you hope?” He replies, “What gives us hope is that biology is capable of making enormous progress. That we've made progress in all other areas of medicine. . . . We ought to encourage people to do more science of the brain. But these are absolutely soluble problems.”

Your group has grappled with some extraordinarily difficult problems today, and thought about some heart-wrenching and sometimes tragic situations.

- As you look forward, what gives you hope?
- And what could you, your organization, or your community do, starting now, to give people like James, Olivia, and those who care about them more hope?
- Summarize key points of the discussion, and consider plans for “next steps” with participants.

Parting Instructions to the Group

Invite your group to visit www.mindsontheedge.org to:

- Check out the interactive feature “What Would You Do?”
- Tell your story by uploading a video to the *MINDS ON THE EDGE* YouTube channel.
- Find more information on the science of mental illness
- Learn about best practices for providing community based support for people with mental illness
- Discover how professionals in medicine, law, criminal justice and other professions are working together to improve the mental health system
- Connect to organizations supporting people with mental illness and their families and friends.
- Become part of the movement to improve mental health services.