



# UNLISTED: A STORY OF SCHIZOPHRENIA

## Guide for Leading a Post-Screening Discussion

*“A compelling and human story, Unlisted makes an incredibly important contribution to our understanding of the mental illness in this country and the challenges we face in confronting it.”* **David Satcher MD PhD, former US Surgeon General**

### Goals For Discussion

Help viewers have a deeper understanding of the following:

1. The emotional toll schizophrenia can have on the entire family
2. Myths surrounding schizophrenia
3. Obstacles to obtaining needed treatment and services
4. Overcoming obstacles, including the role of psychiatric advance directives (PADs)

### Tips For Using This Discussion Guide

- The Guide covers 4 main issues which are the same as the goals listed above
- Questions to ask the group are italicized and have an arrow in front them
- Quotes from the film are italicized in this guide and you may find it helpful to read these out loud to the group
- There is a more complete Educational Discussion Guide available when the DVD is purchased for educational settings

### Starting The Discussion

Consider starting the discussion by asking participants to give their overall reactions to the film.

- *What parts of the story stand out the most to you?*

### Issue 1: The emotional toll of schizophrenia on the entire family

**DELANEY** *“As a doctor, I’ve been working in clinics for the underserved for years. And I see so many people with severe mental illness who are disconnected from their families, it makes me have to think, why is it that I’m not more connected to my dad?”*

In the film, all of Richard’s family relationships are affected by his disease –

- *What are some of the emotions and coping mechanisms employed by Delaney and Richard’s other family members?*

### Discussion Points

Delaney, (A past full of embarrassment, shame, and guilt. Coped by becoming the “parent” and a having “thick skin”)

Delaney’s mother (anger, perhaps blame, not wanting to discuss Richard at all)

Richard’s cousin Michael, (feels responsible, expresses frustration)

Richard's sister, (care provider who discusses the need for setting limits)

Richard's other daughter (Seems cut off from emotions, says she does not feel that he is her responsibility) Yet she invited him to her wedding?

## Issue 2: Myths surrounding schizophrenia

- *What are some of the myths around schizophrenia that were raised in Unlisted?*

### Discussion Points

**Split personality.** Delaney says that she knew her dad did not have split personality, "Dad was always dad". Many people associate schizophrenia with split personality. The medical term for split personality however is "dissociative disorder" and there is controversy over this disorder.

**Violence:** Richard said he did hit people long ago, but Delaney does not describe any violent behavior of her father. Research shows that the vast majority of people with schizophrenia are not violent.

## Issue 3: Obstacles to obtaining treatment and services

### A. The illness causing obstacles

- *What are some reasons that a person's schizophrenia may hinder them from getting treatment?*

### Discussion Points

**Delaney:** "You don't think that you have schizophrenia?"

**Richard:** "No, I don't think I do"

**Delaney:** "Even though you've had all these breakdowns?"

**Richard:** "Yeah, well my breakdowns have been partially internal, partially external"

This dialogue reveals the fact that schizophrenia itself somehow results in half of those affected by it not realizing that they have an illness. This inability to have awareness is called *anosognosia*. Without this insight there is generally no understanding that their situation could be improved.

Another obstacle is that the illness is challenging to treat. Medicines can greatly help individuals, but there are limitations. Medicines are more effective in treating delusions and agitation than they are at treating apathy and social withdrawal. Side effects, such as diabetes, lipid abnormalities, shaking, and others, are not uncommon.

### B. The system causing obstacles

*Unlisted* explores Delaney's past and present efforts to get her father needed services.

- *What are some of the obstacles highlighted in the film?*

## Discussion Points

**Strict criteria for involuntary hospitalization.** Currently about one half of states have an involuntary standard based on dangerousness (a person must be found to be a danger to self or others to be hospitalized against their will). Many family members, and some health professionals, believe this criteria is too strict. Family may witness their relative becoming more and more symptomatic with delusions, paranoia, and other symptoms, and feel as though they have no recourse to get needed care for that person.

**Lack of supportive housing.** Most communities do not have the comprehensive supportive housing like Richard has at Step Up. At Step Up there are social workers, psychiatrists, support groups, job training, and more.

Many supportive housing units only have on-site case workers. Unlike Step Up that offers permanent housing, many places provide only temporary housing (“transitional housing”) and after a certain time the person must leave. In many places a person must have a roommate, something Richard had great difficulty with in the past.

**Families feeling pushed away by bureaucracy,** i.e. when Delaney learns that the consent form she needs in order to talk to Step Up about her dad’s disappearance has expired.

## Issue 4: What things can help people with schizophrenia and their families?

- *In the film, what things seem to have a positive impact on Richard’s life?*

## Discussion Points

- Support of family members, such as Richard’s nephew, Michael
- Reconnecting with his daughter and getting to know his grandson
- Long-standing relationship/trust with treatment team, his counselor and his psychiatrist
- Good community care/supportive housing, with onsite services - Medication

Another important tool raised in the film are psychiatric advance directives (PADs), also known as Mental Health Advance Directives

- *In what ways can you see filling out a PAD to be useful for the patient?*
- *...for the family?*

## Discussion Points

**Delaney:** *“So Dad, this is what’s called a Mental Health Advance Directive. It’s for you to right now, during a time when you’re doing really well, to have control.”*

In the film, Delaney helps her dad to complete a PAD. Though Richard expresses frustration with the process, he does consent to medication and hospitalization in case of a crisis.

Similar to a medical advance directive, a PAD allows a person to both designate a surrogate decision maker and to specify treatment preferences. The document is used when the person who created it experiences acute episodes of psychiatric illness and becomes unable to make or communicate decisions about treatment. In addition, the PAD can help divert an actual crisis because the individual can indicate things that help him/her to get better if they start to struggle, such as a list of people to call.

**Research on PADs has shown that:**

- 1) Once informed about PADs, the majority of consumers are interested in completing one
- 2) It is extremely rare for a person to complete a PAD as a way of refusing all treatment. Studies show that nearly 100% of consumers consent to treatment with medication as well as other therapies
- 3) People that complete a PAD are less likely to experience coercive crisis interventions, such as police transport, involuntary commitment, seclusion and restraints, and involuntary medications

**TAKE HOME POINT**

Evidence shows that PADs can be helpful to patients, families, and healthcare team members and therefore should be a tool that is used more frequently. Anyone can download a free PAD and learn more about them at the National Resource Center on PADs, [www.nrc\\_pad.org](http://www.nrc_pad.org)

Also, available is the short film by Delaney Ruston on PADs, ***Crisis in Control***. This 12 minute film and Discussion Guide, are available at [www.mydocproductions.com](http://www.mydocproductions.com)