How Families Can Manage And Prepare for Crises

A Discussion & Practical Help Guide to accompany

out of the shadow

a documentary film
by Susan Smiley

By Jon Stanley, J.D. & Mary Zdanowicz, J.D.

of Treatment Advocacy Center

Preface

Nearly 6 years in the making, *Out of the Shadow* is a deeply personal film that has truly been a labor of love, as well as a mission. Many years ago, before I started making documentaries for a living, I knew there was one story I had to tell, a story I had no choice but to tell. It was happening in my own life, to my own mother. Her life seemed too strange and disturbing to be true.

Out of the Shadow was born out of my anger about the stigma and vast code of silence surrounding people with schizophrenia and their families. When I learned about how pervasive this illness is, I realized that it's not just my mother's story, it's *millions* of people's story. People with severe mental disorders are all around us, and I am deeply troubled by our society's pervasive misunderstanding of them. And, I am profoundly saddened by the discrimination of people afflicted with schizophrenia and other serious mental illnesses.

In my family no one talked about my mother's "odd" behavior, but we all wondered why she couldn't "pull her life together." After decades of erratic behavior, hospitalizations, no follow through on goals, disorganization and utter frustration, we finally realized that our mother actually was *so ill* that she wasn't *able* to help herself.

As a filmmaker, I knew that the intimacy I had with my mother would offer unprecedented insight into the life of someone who suffers from schizophrenia. I hoped that by showing such insights, I could illuminate realities and clarify misconceptions. In filming my mother and her circumstances, I also wanted to expose the travesties of our public health system, which has so poorly cared for her, that decades of her life were simply lost. It is my sincere hope that *Out of the Shadow* will educate people who have had to care for a loved one who suffers from schizophrenia. Families are not alone on this very difficult journey. It is unfortunate that most of us suffer in silence for too long before finding the support we need. I also hope that this film will help educate people who are not directly affected by the illness of schizophrenia, but simply desire to better understand it.

In addition, I want to emphasize the hope for recovery that we have every reason to feel. My mother's story is an inspiring example of hope. It took decades for my sister and I to learn how to effectively take care of our mother, helping her realize some degree of potential. I have learned that some recovery IS possible if the proper supports are in place, such as stable housing, job training and placement and medication management. Cooperation between mental health professionals and family caregivers has given our family a sense of accomplishment that we never before had, and it's allowed Millie to realize goals she never before thought were possible.

Being a family advocate is not an easy job, nor one any us would have chosen. May *Out of the Shadow* and this accompanying Guide for Family Caregivers offer you tools that will somehow make your jobs a little bit easier.

With Best Wishes,

Susan Smiley

Please check out the film's website: www.outoftheshadow.com for more information and educational materials. You may also email your comments to us at info@outoftheshadow.com.

Acknowledgements

My deepest and most humble gratitude goes to my mother, Millie. If it weren't for her unbelievable courage and willingness to allow herself to be filmed over 4 1/2 years at her most vulnerable as well as all along her journey toward recovery, then I would not have been able to make *Out of the Shadow*, a film I feel is not only powerful but also very instructive on numerous levels.

I am also tremendously grateful to other family members including my sister Tina Kotulski, my father Alan Smiley, my cousin Nancy Ekstrom and my Uncle John Hall. Each of them were very courageous to share their deepest selves in telling their stories about a very uncomfortable and sometimes painful part of our lives. Everyone who participated in *Out of the Shadow* did so with the hope that the film would open the door for many other families to acquire some essential education, realize that they are not alone and inspire hope and healing.

I wholeheartedly thank Jon Stanley, J.D. and Mary Zdanowicz, J.D. for writing this very practical and informative guide. I only wish such a useful resource existed for my family in the early days of caring for our mother. I am also grateful for the vitally important work of the Treatment Advocacy Center.

This guide is for all the family advocates out there who are standing by their mentally ill loved ones, persevering, doing the difficult, but essential work of obtaining the best treatment they can for their loved ones. I wish you success, health and happiness.

Introduction

Running Time of Out of the Shadow: 1 hour

Time Needed for this Guide: 1 - 2 hours

This Guide can be used in facilitated discussions following the film's screening. Or, it may be used as a stand alone aid for family caregivers or patient advocates seeking improved patient care for someone suffering from a serious mental illness.

Objective: To offer practical information and tools to help families, friends and any advocate find and obtain improved care for the seriously mentally ill.

How Families Can Manage
and Prepare for Crises

<u>IN THIS GUIDE, READERS WILL LEARN</u>:

1) **Laws and procedures for the placement in treatment of individuals who have been rendered incapable of informed medical decisions.**

2) **Ways to prepare for a crisis caused by a symptomatic psychiatric disorder.**

3) **Strategies for overcoming legal barriers to the best treatment for a patient at a psychiatric facility.**

4) **Tactics to obtain optimal care from an often unresponsive mental health system.**

<u>DISCUSSION QUESTIONS</u>:

After the completion of the film's credits, ask the questions which appear below. After each question you will see points to amplify and develop during the discussion.

1) **The documentary opens with images of people made homeless by the symptoms of severe mental illnesses, such as schizophrenia. Why are individuals so acutely incapacitated by psychiatric disorders not helped?**

    - In what ways can family members like Susan and Tina prepare for such a crisis?

    - Is there treatment and services available for such people from the mental health service system in your area? If so, what types?

    - If there are treatment resources for these individuals, at what point can treatment providers make individuals incapable of making informed medical decisions accept psychiatric treatment?

- Is Millie's claim that she is always getting kidnapped by the police necessarily a sign of paranoia?

- Tina claims that her mother could keep it together for short periods of time when people visited her. How could this have impacted the ability to get needed treatment for Millie?

- What are the drawbacks of waiting to insist on treatment until someone, who is in a position similar to Millie's, is in extreme crisis?

2) There are effective treatments available to manage the symptoms of schizophrenia on a long-term basis. So then, what factors contributed to Millie being in 17 psychiatric inpatient facilities over a 20-year span?

- Once hospitalized, at what point did Millie have the option to leave an inpatient treatment facility?

- Even while she was in the hospital, why was it necessary for her to sign an authorization to receive a prolixin injection? Did it matter whether or not she had voluntarily agreed to become a patient or been involuntarily placed in the hospital?

- Is there any way in which treatment providers can make Millie remain compliant with her treatment once she is released to the community?

3) In the course of Millie's treatment, what evidence was there of the flaws and failings of her state's mental health system?

- Why, after one of her hospitalizations, was the wait for transitional housing up to 3 months even though she was 2nd on the list for it?

- Is a nursing home the appropriate treatment venue for someone with severe mental illness? Talk about it's drawbacks. How is it possible to create or maintain appropriate care in a nursing home if someone has no choice but to live in one for a period of time?

- Why did Millie have a new psychiatrist, each of whom prescribed different medications, at each new stop in the mental health system?

- Why did each of these new doctors not read her medical records from previous treatments?

4) How did the participation of Susan and Tina help to overcome the inadequacies of the mental health system?

- Why did they feel the need to become Millie's guardians?
- In what ways did becoming her legal guardians help them obtain the best possible treatment for their mother?
- How do Tina and Susan influence the system's treatment of Millie?
- What do you suppose happens to patients without such dedicated relatives to monitor their care in the mental health system?

CAUTIONARY NOTE

The types of available public psychiatric services, procedures for their access, and pertinent legal provisions, particularly those concerning assisted treatment, vary widely from state to state. Hence, all the information presented will not be applicable to a specific jurisdiction. Advise the members of your audience or group to consult appropriate mental health, advocacy and/or legal resources to learn about the applicable service mechanisms, procedures and laws for their state (See Recommended Resources).

TEACHING POINTS FOR THE FACILITATOR

1) REACTING TO AN EXTREME CRISIS

a. When a person is overcome by the symptoms of a mental illness and refuses needed psychiatric care, the law will only permit treatment interventions when there is an extreme crisis. This is normally the case even when the person is rendered incapable of making rational treatment decisions.

b. The criteria that must be met in order for a person with a mental illness to be hospitalized are very stringent. Although the language differs from state to state, most commitment laws require that the person's condition manifest an immediate danger of physical harm to himself or others before being placed in treatment. Being forced to wait until a person is incapacitated by a severe mental illness presents an actual danger, and most often leaves family members and treatment providers waiting for an extreme crisis in order to take action.

c. It has become increasingly evident that restricting treatment interventions to such dire circumstances is a main cause of jailings, homelessness and suicides among those with acute psychiatric disorders. In response to this, a growing number of states have adopted alternative commitment standards that encompass factors such as a person's deteriorating condition, need for treatment, inability to make informed treatment decisions, likelihood of becoming dangerous absent treatment, and the capability of independent functioning. This is a form of an *Advance Directive*.

d. Even in states that have these more progressive criteria, however, simply being sick and in need of care is, in of itself, rarely enough to justify assisted treatment. ***It is imperative to know the standard for treatment***

placement in your state. A summary of the treatment placement standards for each state is available from the Treatment Advocacy Center (Legal Resources section at www.psychlaws.org).

e. The process to initiate the placement in treatment of someone incapacitated by a psychiatric disorder also varies from state to state. A law enforcement officer can take a person that he or she deems to meet the state's "pick-up" standard (which is typically the same as the one for commitment) to a psychiatric facility for an evaluation, although a few states require that the officer first receive authorization from a judge or magistrate beforehand.

f. Under some laws, physicians and possibly other medical personnel can temporarily prohibit the release of a voluntary patient or call for an emergency evaluation without prior court approval. Many states also have a petition process in which an individual can request a court to order an evaluation. Possible classes of permitted petitioners range from "any person" to "interested persons" to family members to designated mental health department employees.

1. Regardless of the manner in which evaluations arise, almost every state limits the duration of evaluation and hospitalization. Most typically, treatment providers must decide within 72 hours either that the person continues to meet the placement criteria and pursue a formal commitment or to release the individual.

2. In most states, treatment interventions are no longer limited to hospitalization. Most jurisdictions now permit assisted outpatient treatment or outpatient commitment, which is court-ordered treatment in the community. There are only 8 states without assisted outpatient treatment (as of this writing they are: Connecticut, Maine, Maryland, Massachusetts, New Jersey, New Mexico, Nevada and Tennessee). Many states allow the use of outpatient commitment under eligibility criteria less restrictive than those for hospitalization. This intensive, mandated and supervised treatment is used much more frequently in some states with laws for it than in others. There are several reasons for this including a lack of awareness of the law and that an order for community care is unlikely in states that predicate outpatient commitment on immediate danger. Despite these barriers, advocacy of a determined family member can sometimes result in assisted outpatient treatment even in those states where the treatment mechanism is rarely used.

2) PREPARING FOR A CRISIS

As detailed above, assisted treatment laws can only be used during extraordinary crises. Thus, those trying to facilitate the care of someone with a severe psychiatric disorder who is noncompliant with treatment are almost always limited to the psychosocial techniques discussed in other modules of this teaching guide. The events necessary to trigger commitment laws, however, can be among the most trying and hectic imaginable. Distraught family members have to react minute by minute to a deluge of circumstances. It is not a time for either efficient thought or strategizing, which is why preparing for a possible crisis is critical.

Possible ways to become "ready" for a psychiatric crisis:

a. Know your state's standard for intervention and familiarize yourself with its provisions for commitments.

The pertinent statutes for each state are in the Legal Resource section at www.psychlaws.org. Your state or local mental health departments may be able to provide materials summarizing them. Some jurisdictions allow direct petitioning for commitments. In these jurisdictions, the clerk at the local court should have copies of the petition form.

b. Learn the screening facility or local emergency room that performs emergency psychiatric evaluations.

When a crisis arises, provide them with treatment history, including past responses to various medications. It is best to provide information both in person and in writing.

c. Alert the local mental health crisis units.

These outreach workers typically conduct on site evaluations and are often empowered to initiate commitments. Also, they are likely to be called by law enforcement to assist in crises involving an individual overcome by a psychiatric disorder. It is best to provide information both in person and in writing.

d. **Similarly, make your local law enforcement agency aware of the person's condition.**

You should do this in case officers or deputies are called to initiate an emergency evaluation or to respond to a disturbance. Eliminating the element of surprise will reduce risk of a call escalating into a crisis. If the agency has a crisis intervention team or other types of dedicated mental health officers, you should try to arrange for them to respond to any call. Again, giving the information in person and in writing will increase the chance that it is available to responding personnel.

e. **Document the person's psychiatric history as fully as possible.**

It is unlikely that treating professionals will have access to the full medical records of a person brought in for an emergency evaluation, especially at first. In *Out of the Shadow*, even the doctors assigned to Millie for ongoing care did not have her full history. Documentation of past treatment can also be used as evidence in commitment hearings.

f. **Keep a journal that documents the person's illness and significant problems it causes.**

Journal entries should concentrate on observable facts. Being able to provide specific dates and contemporaneous descriptions of events is a substantial advantage for someone testifying in a treatment hearing or trying to convince a treating professional of the severity of a person's illness.

g. **Have ready both a recent picture of your loved one as well as a list of vital statistics.**

This should include your loved ones height, age, weight, hair color, clothing, and any pertinent physical medical conditions (like allergies or diabetes). Ideally, keep these in format that allows them to be either faxed or e-mailed to police and mental health agencies.

h. **Keep a list of emergency numbers**.

This includes those for the treating psychiatrist, emergency psychiatric receiving facility, local emergency room, mental health crisis unit, other mental health professionals, crisis intervention team, law enforcement, etc.

i. **Contact your local NAMI chapter.**

NAMI (National Alliance on Mental Illness) is the largest support and advocacy organization devoted to the care of people with severe mental

illness. It is mainly made up of people with psychiatric disorders and, most especially, their families. A local chapter will usually have bi-weekly or monthly support meetings and its leaders are almost always willing to advise on the treatment system and procedures in their area. NAMI's national website, which includes contact information for its state and local chapters, is at www.nami.org.

3) INVESTIGATING AVAILABLE TREATMENT OPTIONS

Those who are the most severely ill often cannot get the services that they need. If you are unsuccessful advocating for needed services for someone you care about, you may want to try some of the following strategies:

a. Research available treatment options.

A person seeking the best possible care for a person suffering from a severe mental illness must first research what treatment options are available. The best and most obvious place to turn is to the professionals presently managing the person's care, but that is only the beginning of a thorough investigation. The leaders and staff of local NAMI affiliates will not only be familiar with service options, but may offer a better "real world" assessment of them than that provided by employees of mental health departments, hospitals, or private community providers. Another basic resource is state or local mental health administrators. But, whether through intention or as a result of fragmented systems, identifying specialized services can be elusive. Never accept a first answer, and know what questions to ask: e.g. does the community have intensive case managers, intensive family support services, residential support services, etc.? Visit the local mental health center or mental health service providers and request a tour.

b. Learn eligibility criteria.

Learning what options there are is not enough because most specialized services are reserved for specific populations. Those advocating for a particular service must also learn the eligibility criteria for these programs. Do not solely rely on an oral determination of whether or not a person qualifies for a particular service; ask for the written policy governing eligibility. Take specific examples from the person's treatment history (for example, repeat hospitalizations) to establish he or she is eligible for those services.

c. **Roughly calculate the financial incentive.**

There is often a financial disincentive for providers to serve those who are most acutely ill - they may require intensive and expensive treatment. One way to counteract this is to document what it costs *not* to provide those services. For a person who is repeatedly hospitalized, the cost can be determined for a specific period by multiplying the cost per day by the total number of days. A state or county mental health administrator may appreciate that providing the needed community services or additional inpatient days to more fully stabilize the person's condition will be less expensive in the long run.

4) ADVOCATING FOR OPTIMAL PSYCHIATRIC CARE

Whether the person is in an inpatient facility or needs psychiatric care in the community, it can be frustratingly difficult to obtain appropriate mental health services from often unresponsive mental health care systems. There are, however, techniques through which a persistent family member or friend can secure action from these typically ponderous and fractured bureaucracies.

a) **Be an advocate.**

While building relationships with service providers is vital, it is important to remain an advocate first and a friend second. By developing a cooperative, personal relationship, family members can demonstrate their value as members of the treatment team. They must not, however, deviate from their primary role as an advocate for optimal care. Disagree with politeness and persistence when cooperation is not possible.

b) **Work your way to the top.**

It sometimes may be necessary to jump over heads to a decision-maker. A negative answer or failure to act is not necessarily final, even if so represented. Jails, hospitals, treatment facilities – every one has an established chain of command. Unless there is a critical need for immediate action, work your way up the chain a step at a time until you get results. In an inpatient setting, for example, an initial request may be directed to a social worker. Follow-ups could be to a nurse, psychologist, and/or psychiatrist. Next up the ladder might be a treatment team leader or section chief, and after that the hospital administrator. Document each attempted contact or conversation by e-mail or fax, which will politely make it known that you are creating a paper trail that can later be reviewed by

supervisors or even in court. Finally, most organizations (public and private) have oversight from a Board of Directors or Trustees. The identity of board members is a matter of public record. Write them a short letter documenting the problems and lack of responsiveness. The Board has a fiduciary responsibility to ensure that the organization's mission is met and will likely investigate and address your complaints. For publicly funded services, you can look for help from your state legislators or even go over the head of the director of mental health services. Well-documented cases have gotten the personal attention of Governors.

c) **Hire an expert.**

If your initial attempts at influencing the system don't work, you can still seek to build leverage that will lead to reconsideration and your objective. If you can afford it, an expert can be invaluable. You must, however, match the type of expert to the situation. For instance, care providers may react more readily to second opinions from fellow treatment professionals while hospital and community service administers are often more responsive to contacts from attorneys. Convincing jail or prison officials may call for a correctional expert.

d) **Enlist the assistance of your local law enforcement.**

For a person who has had repeated contacts with law enforcement, seek help from your local law enforcement agencies. A call from a Sheriff or Police Chief can often lead to the provision of previously denied services. You must help the members of law enforcement that you contact understand that getting treatment for the person you are both concerned about is to their advantage. Not only would appropriate treatment benefit the person and possibly avert a tragedy, it would also remove the burden on local law enforcement created by the person's symptomatic actions.

e) **Contact your local media.**

Local media may be interested in situations that are particularly egregious, heart wrenching, or representative of a systemic problem, especially those reporters who have previously written about mental illness or crime. The publication of such articles will often free up before "unavailable" treatment resources for their subjects. Almost all newspaper websites have reporter contact information. The best manner to sell a story is to start with an intriguing one-sentence summary and then keep your comments to one main issue (treatment, insight, criminalization, etc.). Picture a headline and

make it a theme: “Man Jailed For 10th Time In Five Years Because The Law Can’t Help Him Get Treatment: Mother Demands Answers.”

5) ACCESSING MEDICAL INFORMATION

Sometimes concerns about breaching confidentiality are raised by treatment providers as a reason not to talk to a third party trying to help someone who is receiving or in need of treatment. Sometimes confidentiality is used inappropriately.

a) **Listening is not against the law.**

Even if treatment providers cannot tell you about someone’s condition or treatment, no privacy law prohibits them from taking information concerning a patient’s condition and psychiatric history. In fact, many would argue that a mental health professional would be negligent to not gain as much information about the person’s condition as possible. If nothing else, you may establish a relationship that could at some point be invaluable.

b) Patient has a right to give access.

A patient can always permit others to access his or her medical information. When a provider asserts that this permission has not been granted, never assume that the patient was actually asked to give it.

c) **Some truths about HIPAA**.

Do not be intimidated when someone says HIPPA*.* HIPAA is the “Health Insurance Portability and Accountability Act of 1996,” a federal privacy measure designed to create a national standard for certain types of health care information. HIPAA is often asserted as an all encompassing prohibition of the disclosure of medical information. It does not, however, absolutely preclude families from obtaining information about a loved one’s treatment. For instance, under HIPAA:

- Patients have the right to request copies of their medical records, which can be compiled and saved for immediate use in the future.
- Individuals who have power of attorney or are guardians, as were Tina and Susan for Millie, are entitled to full access to the patient’s medical records.

- HIPAA provides for a formal authorization process in which a patient can give written permission for the disclosure of treatment information to another. The authorization must be specific in terms of what information can be disclosed, to whom, and for how long. Also, such authorizations are immediately revocable by the individual granting access to his or her medical information.

- A less formal process is available in which the provider can discuss treatment under circumstances in which the patient is present with the inquiring family member and the patient has an opportunity to “agree or object” to the disclosure.

- There is also a “best interest” rule that applies when a patient is incapacitated, in an emergency situation, or not available. In those cases, a provider may make disclosures determined to be in the “best interest” of the individual.

- It is important to know that jails and correctional facilities are exempt from some HIPAA provisions and can obtain medical information about an inmate for many purposes, including the provision of health care to such individual. This is important if a loved one is incarcerated and the jail or prison staff is trying to get information from a prior health care provider.

d) Learn your states specific laws.

At least 21 states also have their own laws governing confidentiality. Some state laws may impact the “agree or object” or the “best interest rule.” For state-specific information, consult these web sites:

http://www.cdc.gov/privacyrule/privacy-links.htm

http://www.healthprivacy.org/info-url_nocat2304/info-url_nocat_search.htm

RECOMMENDED RESOURCES

The Center for Missing Adults
www.missingadults.org
Helpline: 800-690-FIND (3463)
Receive informational support and register missing loved one with agency, includes posting picture and profile on website.

NAMI – National Alliance on Mental Illness
www.nami.org
Helpline: 800-950-NAMI (6264)
Monday through Friday, 10am-5pm
The website includes contact information for each state and local chapter. NAMI is the largest support and advocacy organization for individuals with mental illness and their families.

The National Guardianship Association
www.guardianship.org
(520) 881-6561
Some general information on guardianships, but little that is mental illness specific.

National Suicide Prevention Lifeline
www.suicidepreventionlifeline.org
Helpline: 1-800-273-TALK (8255)
A toll-free nationwide number that relies upon local Crisis Centers to provide risk evaluation/intervention/information and referral to local community based services for people who are in crisis and at risk to help prevent a potential suicide or attempt. Calls from family members are welcome; 90% of calls are for non-crisis situations.

Social Security Administration
www.ssa.gov
Includes information on SSI/SSDI benefit programs.

Treatment Advocacy Center

www.psychlaws.org

(703) 294-6001

A national nonprofit organization working to eliminate barriers to timely treatment of severe mental illness. Website has extensive information on commitment laws, including details of those for each state.