

Advice for Families

(2009)

Hi Mark,

Some friends of ours need help. The father is a family physician and the mother works with the church. Their kid is about 22 or so, and was just diagnosed with Paranoid Schizophrenia. He's really out of it, and getting worse. Got any books to recommend? Any writings of yours? They are so hurt and confused. They don't know anything positive; they are feeling hopeless. The psychiatrist said that they will be in the midst of major chaos with him for 2-15 years. He has gotten worse in the inpatient program and is on medication, but is deeper into the illness. Anything he could offer them, remembering the father is an MD but still knows nothing about this.

Hi,

This is kind of a hard question to answer. Undoubtedly this couple and their son are in a great deal of pain and confusion. They would like to find some solidity in a medical diagnosis and prognosis. Unfortunately, it's not that straightforward. His diagnosis of paranoid schizophrenia may well change as different doctors see him and as time goes on. Even the broad prognosis of major chaos for 2 to 15 years is really just a guess; not a bad guess, but just a guess. Schizophrenia, even if that's what it turns out to be called, is such a complex, variable, individual, and especially interactive condition that the diagnosis is not a destiny. What they do can alter his outcome profoundly and far more people with serious mental illnesses do well than most doctors think because we only work with the people not doing well. This is why the public mental health system is undergoing a transformation from the illness centered medical model to the person centered recovery model. Here is some advice:

1) Don't worry so much about learning about schizophrenia as an illness. Learn about what your son is actually experiencing and what it is like to have schizophrenia. He needs empathetic understanding, not intellectual understanding. Try some first person accounts - My favorite is Patricia Deegan. Check out her website.

2) Unfortunately, many people begin treatment in a hospital which can be a very frightening and traumatizing place and make things worse and turn people away from treatment. Remember that the hospital's goal is to get people "stabilized" as fast as possible and out of the hospital. To do that they are often in a rush and use a lot of medications in high dosages fast without a lot of concern about side effects, ability to function on those meds, or long term collaboration. It is very important to learn about medications and how to collaborate with doctors. Start keeping a medication log including dosages. I recently bought two new books by a friend of mine Ron Diamond "Instant Psychopharmacology" and "The Medication Question: Weighing Your Mental Health Treatment Options" because I liked the earlier editions so much. They are written using language anyone can understand. Using medications is more nuanced for serious mental illnesses than most people expect. It's not just a matter of making a

diagnosis and prescribing a medication to treat it. More often medications are targeted to particular symptoms or problems that are getting in the way of the person's life. I attached a brief article I wrote for a presentation in Tokyo called "Thoughtful Psychopharmacology" that describes some of the issues involved in using medications successfully. When I got to Japan I discovered that the Japanese word that had been translated for me as "thoughtful" really meant something more like "compassionate." They wanted me to talk to their psychiatrists about considering the patient's point of view when they prescribe medications. Keep asking yourselves and your son what things are like for him.

3) Since dealing with serious mental illnesses depends so much on the person who has the troubles treatment is not something that can be done to someone, it must be done with someone. Therefore, the foundation of a good treatment is not a good diagnosis; it is a good relationship with the treatment professionals including the psychiatrist. I work on building trust first. Spend some time finding a good match in the community who will stick with you and your son through the ups and downs. There's an article I wrote about what to push for in a doctor called "Ask Your Doctor about Recovery" at <http://mhavillage.org/Web%20Articles/12AskYourDoctoraboutRecovery.pdf>.

4) The recovery movement is mental health's equivalent of the hospice movement. It is designed to help guide people through a series of stages as they move towards recovery and a life with dignity. You can find a copy of a short book I wrote about recovery at http://www.village-isa.org/Village%20Writings/writings_hp.htm. There is a whole world of books and articles about recovering from serious mental illnesses and self help you can find on the internet, many written by people who have themselves recovered from serious mental illnesses including schizophrenia.

5) Bill Anthony and others at Boston University have done a lot of work on what helps people recovery. When they surveyed people who have recovered 4 items were repeatedly included: 1) Medications (Recovery is not an anti-medication or anti-psychiatry movement despite the fact that it helps people who don't believe they have a mental illness and won't take medications.) 2) Someone who knows you well to help in crisis, not a stranger in a hospital or emergency outreach team, 3) Someone who won't give up on you, who will stick with you believing in you when you're too hopeless to believe in yourself and won't let you give up on yourself, and 4) God.

6) My own work focuses on: 1) Emphasize patient education, collaboration, and self-help, 2) Focus on hope, 3) Try to keep people in their lives, 4) Incorporate rehabilitation and adaptation, 5) Focus on impact on self image, and 6) Promote long term, more personal doctor-patient relationships. Serious mental illnesses create challenges in all of these areas.

7) The end point of a successful recovery is something like, "I wouldn't have wished this illness on my worst enemy. The suffering and the destruction have been enormous. But in a strange way it has also been a gift. It has helped me find strengths inside myself I didn't know were there and to become the person I am today." Unfortunately, serious mental illnesses often strike when people are young, before they've fully developed strengths and identity. I believe the most important treatment goal is not symptom relief, but for your son to develop strengths and resilience from this terrible experience and not develop crippling and dependency. My sons are presently 20 and 22. I have seen them grow and

Exploring Recovery: The Collected Village Writings of Mark Ragins

develop and I have dreams for who they will become. While I'm sure their lives will lead them in unexpected directions and I will be left wondering what happened while I try to keep up, I doubt I will face anything as challenging as you are now. I hope we can both take pride in who are sons grow up to be, whatever their losses and difficulties along the way.

Take care,

Mark Ragins, MD

www.mhavillage.org