

PART 3

When our son attempted suicide, that's how we found out he was up, and I think – I don't know if it's been twice he's tried it since then.

Narration 22

Schizophrenia seems to strike out of nowhere. Most often, patients and families do not have the knowledge, skills or support they need. Frequently a crisis situation abruptly introduces the family to the disease.

It probably is a genetic disorder, but there are some thoughts that it could be secondary to a viral infection that people have at a particular time during their gestation. The research has not been conclusive on that. However it comes about, it does lead to a situation where the afflicted person doesn't have good boundaries between his internal reality and his external reality. This leads him to misperceive his own thoughts as hallucinations of one sort or another, usually auditory kinds of hallucinations, and their judgment is frequently very inappropriate, because again, the internal and external realities are not in sync, and they may be responding at one time to an internal reality, instead of the outside reality, you know, and be making judgments which are simply out of step.

Initially, I felt like it was like the flu. This was going to go on for six months, and then it's going to go away. But the longer we got into it and the worse it got, the more we realized that this is, this is a way of life. Looking back, you know, we've come a long way.

And you don't understand it. You think that she's going to get better and you don't understand it. I get so overwhelmed with my daughter, so I just hyperventilate sometimes.

Narration 23

The National Alliance for the Mentally Ill's, Family to family educational program, empowers families to be part of the treatment team by giving them information about the disease. It also provides a much needed supportive environment.

Family to Family gives families a sense, first, I think, of not feeling alone and isolated, which is the initial impact of the trauma of mental illness. That suddenly people and – life seems to almost fall away. So, the first thought we have is to get people together, so that they can understand that they're not alone. It's a place where we can begin to learn what is necessary about coming to terms with an illness that, for most people, is a chronic illness. It's a long road, we want to assist you with it. This would be an enormous help to you. Families need a great deal of information about the illness, but in their day to day lives, they need to know, how do I address someone who is in a psychotic state? How do I deal with somebody who can't take this – or won't take this – medicine. So, it's very,

very beneficial for family members to get a (inaudible), a sense of having their radar down in a mental illness, and I think we get that in Family to Family.

For the first time in five years, we knew he was on the correct medication, because we were monitoring it, sorting it, putting it in morning and evening boxes for the week, and we knew he was taking the right amount. He got to a point where he could actually work, and you know, that's been amazing.

Narration 24

Although a cure for schizophrenia has not been found, research does show that the individual with schizophrenia will do better if family is involved in treatment.

I can't overstate the importance of the family's involvement and treatment of people with schizophrenia. With the, as family members know quite well, you're the support system, often, for the patient. Often, you've been heavily burdened over the years, challenged by a treatment system that doesn't respond very well to your needs, by a family member who has lots of needs and it's hard to know exactly what to do. And, so the times that you may feel frustrated and burned out about the prospects of remaining involved. I can tell you as a doctor, as a person who's worked with people with schizophrenia for many years, that having the family involved makes things much better.

It has been very difficult for me to let go of my expectations of Ronald, because like I've said, Ronald is a very bright young man, but because of this mental condition that he has, he's not able to function, he can't work. We've tried that and he just can not stay episode-free long enough to maintain a job. So, and it's very, very difficult to accept the fact that he is what he is, and he has his limitations, and they are what they are.

Narration 25

Often family members don't understand the mental illness or can't agree on how to manage it. Anger and frustration can transform a once happy family.

Families come into the Family to Family education program with a lot of sadness, a lot of grief, a lot of guilt, one of the things that, you know, families lose when their family member has a mental illness is that their own hopes and expectations for their relative has to change. Lowering expectations is part of the information and education that we provide to families. Letting them know it's okay to, to accept less than what you thought you were going to have with your family member. And that's such a crushing disappointment for families, and families need to understand that this is a part of the illness. This, the person who has the illness changes.

In the beginning, when my husband was diagnosed with Schizophrenia, the medication, well, because it was so long ago, the medication that they were giving him, you know, just kept him so, I guess maybe non-responsive is a good word.

Narration 26

Medications are a source of concern for most families. And there are no easy answers. What works for one person, may have devastating side effects for another.

We wish there was a cure for schizophrenia, but we're unfortunately, nowhere close to developing the cure. We have effective treatments for some components of the illness, we have effective treatments for reducing relapse rates, but we don't have a prevention and we don't have a cure. It's a complicated issue about how to choose the right drug for each individual person. In general, they have similar therapeutic actions. They work through similar therapeutic pathways, and we don't have any good way to tell that one drug will work better for an individual than another. They do differ, however, in very important ways, in the side effects that they have, and patients will differ in their experience of these side effects. So, what the doctor needs to do is to figure out with the patient, which drug is most likely to have few side effects, not be bothersome to the patient, and not impose any risk in and of itself. Rather, try to get a better therapeutic effect because the patient will be more likely to take the medication.

You know, he was doing his own medication thing for awhile, you know? The prescription says, take the medicine this way, but that's not what he was told to do, so he was taking the medicine another way. So, I mean, it's just so many areas that we have to be vigilant in, you know, for our loved ones.

Narration 27

Medication compliance is a problem all families face. But if medications are not taken consistently and correctly, crisis situations may arise.

Responsibility for medication taking is often a very, very thorny issue between patients and families – especially if the person lives with his family members – and here's what the problem is. All of the patients that we're talking about here are adults, and as adults, we're supposed to be responsible for ourselves. At the same time, as a family member, we notice that your family member, patient, isn't taking his medicine when he should, seems to be skipping doses, seem to be forgetting them. At the same time, when you draw this to his attention, in many ways, correctly, he's annoyed. Who are you to tell me what I'm supposed to do? Don't butt into my business. And that's a very difficult situation to be in. It's a situation that can sometimes be dealt with by a family meeting with the clinician, where it's discussed what the role ought to be, and this is brought up in a context where nobody's angry and where the problem of medication taking hasn't happened yet. Raised in the kind of way of, well, if it were a problem in the future, is there a way that I could provide you reminders that would be helpful to you in continuing to take your medication, so that you're acknowledging the person's independence, and your family members need for independence and

self-responsibility, and at the same time, providing the help and the support that you would like to provide.

On top of his mental illness, he became a severe diabetic, so he has to do his finger stick every day and check his blood, watch his diet.

Narration 28

Unfortunately, individuals with schizophrenia are at increased risk for multiple medical conditions. In addition, medications prescribed to manage schizophrenia may increase the risk of developing certain medical conditions such as diabetes, high cholesterol, and obesity.

People with schizophrenia and other severe mental illnesses have very – very commonly suffer from co-occurring medical problems. People with schizophrenia have 2-3 times the rate of medical problems as people who do not have schizophrenia. So, it really is a double whammy. You have schizophrenia, why should you get something else? Unfortunately, it happens. So, what are the reasons why? The reasons have to do, we think, in part, with health behaviors, and one health behavior is smoking. We know that 70-80 percent of patients with schizophrenia smoke cigarettes. That's about double the general population or more. And we know that cigarette smoking leads to problems with breathing, with cancer, with emphysema. So, that alone really puts people with severe mental illnesses at risk. Other reasons that people with schizophrenia have trouble with medical problems have to do with the treatments that we provide. This is something that really troubles professionals, it trouble me as a psychiatrist. We are getting more and more information that the medications that we prescribe, may be associated to diseases like sugar diabetes. So, that the medication may cause the body to have more difficulty in regulating sugar.

Narration 29

Unfortunately, substance abuse is common among people with mental illness.

Substance abuse is an extremely significant problem for people with schizophrenia. It's one of the most pressing problems facing people with the illness, families and clinicians. The data suggests that more than 50 percent of people with this illness are abusing alcohol or street drugs. An even larger number abuses cigarettes or nicotine, and it's a significant problem, because the biochemical, the brain effects of these substances tend to counteract the effects of anti-psychotic medications that patients need in order to function effectively in the community.

I know he's not working to the capability that he had before the onset of the illness, but still in all, he's working, and he likes to leave the house, and he likes to work, and he forces himself to go when he doesn't want to go, because it gives him something to do – something meaningful – and he doesn't sit around the house, thinking about how miserable he is.

A job is just the blessing, because it gives him self-esteem, it gives him a whole different outlook and shows him that he can do it.

Narration 30

Supportive employment programs provide the opportunity to regain self esteem and social skills.

One of the more effective treatment strategies that we have for helping people with schizophrenia, most people with this illness have significant problems fulfilling social roles, and social skills training is a way to help them to recover skills that they once had, or to teach them new skills that they need in order to have more effective quality of life, and be more effective in their social roles.

Yes, I have had legal issues with Ronald, many, many times over the years. Ronald has been in trouble with the police, he has been locked up, and that's a horrifying experience, because to see your loved one carted off with handcuffs and shackles off to jail, you knowing that he's mentally ill, and that he really wouldn't hurt a fly if he was in control. He has been locked up at least a dozen times for that, for getting into trouble with disorderly conduct mainly, disorderly conduct, and that's horrifying, because once they get caught up in that legal system, you can not get them out. I don't care how hard you try, they're in there until they come to trial. You just don't know which way to go, what to say or what to do. And sometimes now, I know my son can get very, very violent when he's going through some of his episodes, and that's another situation all by itself. I mean, I've had to call the police, I've had to have him locked up, I mean and that's a hurtful thing.

Narration 31

Many families caring for individuals with schizophrenia have on-going interactions with the police and legal system.

Our systems aren't really set up to respond to people in crisis. Certainly, the way that people have historically been responded to when they're in crisis is through an emergency treatment order, which is an order that enables a facility to hold somebody, in essence, to bring somebody in for an evaluation for 48 or 72 hours, and during that time, they determine what the treatment needs are and whether there's some justification for treating the person for a longer period of time. If, in fact, the person meets the criteria set forth in state law for civil commitment, then there is authority to get a civil commitment order, and then the person can be held in an inpatient treatment facility for a period of time, until their condition stabilizes. Usually, to get a civil commitment order requires a finding that the person is dangerous to himself or others.

Narration 32

Families can obtain the authority to make decisions for a family member who lacks the capacity to make sound decisions due to mental illness.

There are different types of powers of attorney available for people with mental illnesses. One is over medical decision making, and another is over personal property. And there are some people who might be perfectly capable of making informed medical decisions, but can't manage their own property or their own money, and vice versa, some people may be able to manage their own affairs, but can't make their own medical decisions. So, there are different types of guardianships that might be available under state laws, limited guardianships or full guardianships. Typically, to obtain a guardianship requires going to court and requires a judicial determination that the person lacks capacity to make those kind of decisions. One way to circumvent that very complicated procedure is through psychiatric advanced directives, where, when a person is competent, they designate who they wish to make treatment decisions on their own behalf if they lose the capacity to make those decisions.

I think that one thing we forget sometimes is that the one person who wants to be – who wants our loved ones better more than we do are themselves. I don't think any of them enjoy being the way they are, and I think that the medical providers have to take that into account when they're dealing with these people. They're not just numbers, those are not statistics, they're not people to play with, with medicine. I mean, these people are disappointed the way their lives came out. I'm sure every one of them would trade places with anybody, not to have what they have.

Narration 33

To continue your education about mental illness contact your local NAMI chapter and inquire about Family to Family programs. Remember family's participation in care improves patient outcomes.