

Schizophrenia Narration

PART 1: BRYAN'S STORY

I've spent many days, maybe even weeks at a time, hibernating in this room, the blinds pulled down, not even turning the T.V. on, just laying in bed and wishing for the end.

Narration 1

34 year old Bryan lives at home with his parents, Bill and Sue Zambiasi. He's currently being treated for a chronic mental illness at the VA Hospital in Baltimore. His parents recently became more involved with his treatment.

That was probably the toughest time that I remember. It was three years ago, I think he pretty much hit rock bottom and he took mom and dad right down with him. So, it's been a very rocky road, more than anything for mom and dad, I think, because they live with this every day. It is, even though, scary, even when he's up. Because you know, when he's down it's depressing, you don't know what to say, you know, he won't come upstairs if we're over here, he just stays downstairs and mom and dad will call him up for dinner, he'll come up, he'll eat, he'll go right back down. And that's, you know, we're all looking at each other like, what's the matter? How long has he been like this? That kind of thing. And then when he's up, it's like okay, how long is it going to last? Is he up because the medicine's working and he's on an even keel? Or is he up because it's not enough – is he actually on a high because he's not taking his medicine or he is taking his medicine? So, it's always a guessing game. It frightens me because I feel sad that it has happened to him, and I know how badly he wants to be normal – whatever normal is – but I know that he very much wants that. And I want that for him, and I know how hard it is for him not to be with his children, I know that breaks his heart. You know, for that sake, of course, I wish him to be “normal” too. I wish he didn't have this illness.

Narration 2

For Bryan and his family, increased family involvement has been extremely helpful.

I bet that feels good. (Child giggling) He got it again!

Narration 2a

The purpose of this video is to demonstrate some of the challenges and benefits of increased family involvement in the care of patients with mental illness.

When I first met Bryan, I was a nurse on the inpatient unit – really out of touch with reality, in many, many instances, just feeling so hopeless and depressed.

Narration 3

In group therapy, Bryan shares the devastation of his illness and some of the frustrations he's had in getting his family to understand his illness.

I believe it's taken my marriage away from me and I've been unable to work for the last 4 ½ years. In about 2000, I tried to commit suicide using exhaust fumes from my car, and that was probably the lowest point that I was at. My family has a hard time understanding that you can't just pull your boot straps up and get on with your life. It doesn't take a week to get better. Like I said before, it's been about 4 ½ years now, since I worked, and it's hard for them to understand how come I'm not doing it faster. It's not a matter of trying harder.

I think without therapeutic intervention, he may not be alive now, and a successful therapeutic, in this case, required the family, and without that full treatment, I'm not sure that he would be alive today. I think he certainly would not have any hope or feeling that the can achieve independence.

Narration 4

Dr. Butchart encourages Bryan to bring his parents for a family session.

The first thing I'm wondering is how much can you count on your family to support you when you've got, say emotionally laden times in your life?

I guess I really can't count on them for a whole lot. I mean, they feed me and give me a roof over my head, so I really don't expect much more than that. They try to understand the illness. They go to (inaudible) meetings, but I still think that they don't quite have a grasp on it. They expect things faster than what they're happening.

I think it would be helpful to have your family come in and try to work out a way that you can talk to each other?

That might be good. It would be nice to be able to talk to them without being afraid of making waves. When you get them in here, they're going to say that, well, we always help them. There's no reason to feel that way.

Well, let's say they said that and you had your response to it. Then we could put that behind us and get on to something else.

Yeah, that wouldn't have to be the main topic, but –

If there were a main topic, what would you pick?

I just need more time without them pushing me out the door.

So, you think it would be helpful if they came, and you would like to tell them that you need more time.

Yeah.

Narration 5

In a family therapy session, Bryan and his parents discuss the progress that's been made during the past few months. During this period of time, there's been increased family involvement and Bryan's been participating in a supported work program.

I remember talking to you a couple months ago, and maybe this word is too strong, but you both sounded like you were in despair over ever being, having a life of your own again.

Or for Bryan having a life. We were really concerned.

-- more so than ours, but yeah, despair is probably a good word.

How have things been going?

Excellent, since – what was it, three months ago when we came? Remarkable difference.

Can you describe the difference that you see over the past few months?

I think when we came three months ago, he was definitely overmedicated. I mean, he couldn't stay awake during our meeting. And uh, now he's working. I meant that's a remarkable difference.

How do you see it?

It's definitely changed. I'm going to work, I like going to work, my motivation levels a lot higher.

How do you get to work?

I drive myself to work.

Have you always been doing that?

There was a period of time when I was overmedicated and I couldn't drive myself.

One of the problems you mentioned was overmedication, and we dealt with that by arranging for you to manage

Well, I'm still noting the pills, but like, Bryan does fine taking it himself.

Bryan, how do you feel about having somebody else manage your medication?

I think it's fine. It's my mom being mom. It's kind of nice for her to be there.

I've heard that you often email Dr. Butchart with information or questions and what not.

We started emailing. We started emailing Dr. Butchart when things were really going down the tubes, and now it's just for general information. I don't think I've emailed either one of them for a couple of months.

It's good for them to be able to vent some place to somebody.

So, you didn't mind them writing to me?

No, that really didn't matter to me.

But it feels so nice to be a family again. I really feel like we have a better rapport.

Tell me a little bit about work, too. How's that going?

It's going well, although I don't remember the stuff I used to remember, which is kind of frustrating. Some of the basics, I've lost, but actually getting up and going to work, and making a whole day of work is a pretty good goal for the day.

Do you notice any difference in him since he started work?

He's not sleeping nearly as much, of course.

Right, that was a problem at one time.

Right, and he does come home and take a little nap.

Yeah, but it's like he has a purpose in life now. You know, before he was kind of drifting, and for months he would live in his basement. Sometimes you'd only see him at mealtime.

What about this down period? Have you thought about maybe talking to your parents about it?

Well, it's kind of opening the past. It's more scary than anything else. You don't know how far down you're going to go.

Do you prefer not to share those kinds of feelings? Being scared about something?

Pretty much, it's hard to get it out of me.

Would you want to save your family from this? Why wouldn't you tell your parents?

It would be like putting on a false alarm, maybe.

How could things be better?

A lot of it's got to come from me talking more about the times when I am down, and trusting that they can hear me more so than what I give credit to.

So, to take a little bit of risk and letting them know that maybe you're not having a good day. It's okay.

Yeah.

Because you know, when I hear your dad and your mom talking about how you've been doing, they're like beaming. They're so happy, and the thought came over me that it might be really hard to say, well, the past three days I haven't been so good.

Yeah.

It may be a little tough.

Can you put your finger on something you might like to do now? A next step?

I'd like to see him obtain some more – some independence. I'd like to see him learn how to handle his money. I'd like to see him get his own place. I'd like to see him have a job, where he could be totally independent.

I'd definitely like my own place, eventually. I can't really see it right now, because it's a lot of pressure.

Narration 6

Bryan's parents became involved with the National Alliance for the Mentally Ill's Family to Family program a few years ago. This free 12 week course helped them learn about mental illness and to be more involved in Bryan's care.

After family to family, Bill and Sue became participants in their son's treatment, rather than observers. And I think that's very fortunate because had they taken that other path, I think Bryan would not be where he is today.

Well, as a family member, we know how isolating it can be, and we feel like many times, we're the only ones going through this experience. You know, we're the only ones that have a relative that's mentally ill.

Your relationship with his therapist, his psychiatrist, his social worker, whoever – that is key for any kind of success, because other than that, you're the voice crying in the wilderness on this. Nobody knows you exist, and they don't know you from Adam.

Narration 7

To get more information about mental illness, Bryan and his family attend educational workshops for veterans and their families to hear the latest from experts.

What is family education and support? First of all, it's information about the illness. It's very hard to cope with a problem if you don't know what it is, so the first critical element of this is information. The second is the capacity, in an ongoing way, to problem solve.

Bryan told us about the conference and told us he wanted us to come. He said he signed us up, and I was really pleased to hear that because any info we can get is a good thing.

And we're a family. We're together in this, you know? And uh, as sad as the whole thing is, there's a joy in the successes. It's nice to be together.

This is Nina, the largest cat, yes. A calming sense kind of comes over you when you get around him. You have to use your patience, or else they don't want to be bothered by you.

I think the lines of communication being open with Bryan's family has made a huge difference in his treatment. When the family observes something at home, maybe things aren't going so well, maybe he's starting to isolate more, maybe he's getting a little resistant about taking medication, they feel open to call, let us know, so all that is open now, to discussion, so we're all on the same team and I think that's what's important. The clinicians, the family, and the patient. We're all part of one team with a set of goals, and we're all working together. So, that just makes all the difference in the world for me.

Yeah, I don't spend too much time down here any more, or fall in the trap of wanting to stay by myself. I get out as much as possible, just to socialize with the little people that I do know, and try to be more aggressive doing other things than just sitting in here. It's taken a lot of work on my part, going to classes, talking to other people, going to my therapist regularly, taking the medicine that I've been given. It's been a lot of little things and a long time to come. It's been about six years.

Narration 8

Bryan and his family know that there will be good days and bad days. But, they also know that because of increased family involvement, both Bryan and his family are better off and there's more hope for the future.