Shared Experiences of Wisconsin Families of Adults with Schizophrenia

A Compilation of Reflections On Experiences from Mothers, Fathers, and Adults with Schizophrenia

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Dear Participants,

Since the Winter of 2000, we have conducted interviews with close to 300 families who have an adult son or daughter with schizophrenia. We are very grateful to all of you for sharing your time, experiences, and wisdom.

In appreciation, we assembled this book of quotes for the many mothers, fathers, and consumers who are participating in this study. Much wisdom, love, and pain are expressed in these quotes. Some of the comments may surprise you, others will ring true to your own lives, and some may help you see both similarities and differences between your experiences and those of other families coping with the challenge of mental illness.

While assembling this Book of Quotes, we tried to balance our desire to use your words with the need to protect your anonymity. We consequently altered information that could identify you or your family, and made some editing changes for ease of reading. We believe we succeeded in keeping your sentiments intact while protecting your privacy.

Thank you for welcoming our interviewers into your homes. We have learned a great deal from you and look forward to our next visit. There is a great need to further our understanding of the challenges faced by families coping with the care of a son or daughter with schizophrenia.

Sincerely,

Jan S. Greenberg, Ph.D.
Marsha M. Seltzer, Ph.D.
# AGING FAMILIES OF ADULTS WITH SCHIZOPHRENIA: PLANNING FOR THE FUTURE

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How Mental Illness has Affected our Lives

On the upside...

I've learned life is a gift to be lived. No matter what, make the most of it.

We are people and not a diagnosis. We are separate from the illness. Problems are difficult, but my family is loving and caring. We have much respect for our son for being able to deal with this.

I think his illness has taught me to really look at priorities in life and just see that what really matters is relationships between people and what people are. And not what they have or what they pretend to have.

Even the bad days are learning experiences. Sometimes the bad turn out to be a good thing because you learn a way to get help and how to give help.

It makes me a kinder, more compassionate person, non-judgmental person. It keeps you in touch with what's important in life (like family), with less about material things.

It's been a great learning experience even though I wouldn't have picked it. It’s made me a great advocate.

It was a huge shock and very painful after his diagnosis and breakdown took place. Yet some of my children have indicated that they've grown due to his illness, and have come to realize more compassion for people with health problems.

For so many years, I felt like I was dumping so much into this well, this bottomless pit. In these later years, the bright and indomitable spirit of my child has prevailed.
On the downside.....

I feel nothing anymore, when it comes to my son. I try not to feel. I try to numb myself, so that whatever he’s doing doesn’t hurt me anymore. When I have him in the car, or I pick him up, and I still spend time with him, when he starts talking about what he’s gonna do, I just go numb.

Trying to keep things going and trying to maintain a positive attitude for this person that I care about has really left me exhausted, and has gotten to the point where it’s become a major health issue for me. So now I’m struggling to find something that will work for him without destroying my health too.

Living with a person with mental illness has made my world smaller.... hardest of all is limiting the people we share this with in order to respect his privacy. That means we live an incredible amount of lies.

I was working at my job and that was very demanding in several cases. I had to put my life in jeopardy at age 64. I didn’t expect anything like this to happen— she was a beautiful and talented girl.... there was a ray of hope until she went off her medication and had a relapse and it started all over again. I get very depressed....I’m just afraid to expect anything to go right.

I feel sometimes like the saying, I have to walk on egg shells. I feel like I have to do that because, even though everything is going well now, sometimes, I can say something and she misinterprets it and she gets very upset with me. She can be just as dear as anyone would ever want for a child. And the next minute be very hurtful.

He’s afraid for me to be away from him. It seems like the older he’s getting, the more he wants me to be there all the time. But he gives me no privacy anymore, and he figures whatever is in my room is his too..... I have no privacy and that’s really bad for me.

It’s been a killer. It’s just changed my whole life. Here was somebody who was a National Merit Scholar and on his way to really contributing to society, so active and an all round gifted person. To see that gone because of the illness. It was so hard because I never thought I would ever have to worry about him taking care of himself. The hope has gone out of my life.

When he was a little boy he was very cuddly and very quiet. And then in 8th grade there was a personality change. And I spent a lot of nights crying. It was just like he had died and somebody else had moved in. And I missed the old Joshua.
Contributions of the Son/Daughter to the Family

I got a bad hip -- he does all my vacuuming, washing windows. And he keeps up all the yard work here, and he’s very, very thoughtful with me if I’m sick. I had the flu a while ago, and I have trouble with, dizziness, vertigo. He was so attentive. When I wasn’t eating, he kept on saying “you gotta eat, you gotta eat.” So he warmed up soup a couple of different times. He put it down for me, “Now eat,” he’d say. “Now you gotta eat.”

He usually will do anything for me, and I mean, there’s been times where -- one time, years ago, my car, the transmission went out, and I was working way out in Amherst at the time. He came right out there to rescue me and drag the car away, and get it fixed and everything.

She helps me take care of the grandchildren. She gets great delight in taking care of the grandchildren and she has great pride in them.

And she’s very good hearted, she helps me and right now, she’s a blessing because her father’s disabled and she has lots of patience with him. And she’s worked in a nursing home, so she’s very good with him.

I think he is so afraid that something’s gonna happen to me and because of it, he comes here every weekend and helps me. And does all the work around that I need. He does my shopping and takes me places where I need to go.

He does want to help me with the grass, and he does want to help me with other things. He’s a great help, he really is. But I have to make a big sacrifice and not fear him in order to have him help me.
Stressful Times

I think he has almost like a panic attack if I should be away for any period of time. I was gone pretty much one day, and he was over by my youngest daughter, crying, and thinking that something major or bad was happening to me. And I was just having an outing without him.

He’s very demanding and manipulative...he becomes angry and agitated if he doesn’t get his way. And he’s constantly swearing at us, putting us down and then turning around and asking for things from us like food and things that we should do for him.

She just walks in and out, in and out, and speaking so loud, and telling us this and telling us that, and some of it has to do with things of her past which don’t relate to anything of the present. And, then she gets mad at me cause I don’t respond to anything she says.

He needs to be told quite a few times before it sinks in, and I don't know if it's just because he's being lazy, or if he's just not getting what we're trying to say to him. We have to repeat so many times. It is really hard on both my husband and I. This illness is so hard to understand.

We do go out to dinner once in a while or to a movie. I’m very much ill at ease at any restaurant because I don’t know when he starts turning around what he’s hearing. I’m afraid he’s gonna jump up and sock somebody.

I work third shift. He tends to drink sometimes overnight and when I come home in the morning, I come home to a person that has been drinking too much, and I don’t need that. He tells me it does quiet the voices. This drinking is very hard for me to contend with.

During the time that she was ill, she would just take off. We didn’t know where she was for quite a while and then she would call up and she would be a totally different person. She would use very bad language, she would swear at me, she’s very distrustful, of all in the family.

She calls me 5-6 times a day. She tells me that I’m her contact with reality.
Coping

My faith in God. When he first got sick, each morning I'd read from the Bible and that got me through the day.

Prayer helps me more than anything. Sometimes your prayers aren't answered right away. It took five years, but she got much better than I ever imagined.

My job. I need an outlet to not think about it and still be productive and feel good.

Crying, sharing with others what's going on, especially with others who understand.....breaking away and getting time out mentally, praying and focusing on one day at a time.

I don’t like to say his illness caused the drinking. I always enjoyed drinking but I’ll tell you when I started to see the pain that he was in and his suffering, it made it a lot easier to have a drink and maybe two and then it got to be three, four, five drinks.

I often try to remember her as a little girl, before she started doing all the horrible things.

The demons take over...and when this happens it’s so hard to reach him ...... sometimes I go up and hug him and hold him and you know, try to bring him back to reality, I’ll hug him and say, “Philip, you’re in my kitchen or you’re in the living room, this is Mom.”

I don’t have the TV anymore because I thought the TV bothered him. And sometimes he gets a little pushy, he’ll talk in my face. But as long as I control myself, and I walk out, he’s fine.

Over the years I’ve learned not to aggravate or agitate him when he’s in that mood. I just listen to him talk at random. I just go along with him and try not to correct him or say that’s silly. And I try to guide him when he tells me or has a thought that I feel is really wrong and off. I say to him, “Let’s talk about this.”

I tried too hard to help him, and to make hopefully, make his life better. And once I learned to let up and let go, it seemed like it was easier for me.

I’m trying to push him as gently as I can towards independence without really placing unrealistic demands and I feel like that’s my daily struggle -- to help him with that.
The Loneliness of Mental Illness

He’s always telling me how lonely he is. He wishes he had a girlfriend.

She’s pretty isolated socially. It has been really hard because she had a lot of friends in college. Now one’s married and has a baby and the other one lives far away. .. I think as she’s gotten older the differences between her life and theirs is becoming more evident to her. So she doesn’t initiate contact with them anymore. I think she’s afraid, in a way, to cut us off because we’re all she has.

He doesn’t know what to do with himself and he needs a friend. He did get an apartment at a time with a young man. But that didn’t work out because this young man was just using him for money. And it turned out to be, sort of a disaster.

And I think she enjoys doing things with me. But then I guess I’m her only outlet because she doesn’t have any friends anymore. High school friends have gone, college friends are gone.

I’m the only person she has, she has no friends here, her brother lives in Oak Creek and Schofield. Sometimes when he is here, we all have a little visit so that’s good. But there’s no one in her life to any extent except me.

He always had a lot of friends when he was growing up. Then he was diagnosed, and went to the hospital, and then, the friends, really sort of disappeared.

He has a hard time socially. He will go and find friends at the bar, even though he’s not drinking, because those are the people that will talk to him and not think he’s different.

His life is so hard because he is ostracized because of his illness. It sets him apart and makes him very different than most people.... They don’t understand, they don’t give him a chance. Anyway he deals with this and lives with it, and is an intense loner.
Money Troubles

We’re having difficulty with him right now; he went ahead and bought property in another county and a land contract that we knew nothing about. And then he called up the real estate company and exchanged it for two lots in a different city. So at this present time, we’re trying to get his money back. . . . He’s just not capable of handling his money.

He has cost me a lot of money. When he was having a hard time paying his bills, he actually took money from my account, and my husband’s account. I’ve always covered his debts otherwise. He never spends money on himself. He more or less charges and gives to other people.

Even though I live in a nice house, I have a very large mortgage. And between both of our incomes, I’m retired, we are more or less keeping our heads above water. He has 3 major credit cards, and he’s got them charged up to the hilt. He’s kind of treading water on that and I’m paying them. I had a credit card at one time, and he charged up that without my knowledge and I’m still paying that off. He’s just ruining me financially.

He’s very vulnerable and if somebody tries to make friends, unfortunately many times it’s to take advantage of him. A few years back, he was working and he was making all kinds of money and he was not interested in spending. And he’d just give it away to folks who promised that they would pay it back, which of course they never did.

In 1991, when she came home, she was deep in debt. I bailed her out to the tune of $40,000 paying credit cards and hospital bills and all kinds of delinquent taxes and so forth. But when she went off her meds in 1998, she ran away and was gone for a week. She ran up another $6000 on her credit card. And this time, I’m 70 years old, I’m living on a limited income.
Medications

She’s a joy to have, to be around since she’s begun taking Clozapine. She’s just been a pleasure to live with. Since I’m a widow, she’s good company.

Since he’s been on Clozaril he is easy to get along with. Before that, there were some times when I really was a little bit afraid of him because he was not stable. But now he’s a very...very nice person to have around.

I’m just overwhelmed that he came out of all this hostility and, you know, just a pill, a medication could do it.

And she doesn’t blow up at me like she used to do. I’m sure that’s partially maturity and partially the medication.

I think the medicine he's on right now affects him, being sluggish and not wanting to do things. I know they're trying to help him in every way they can, but I don't think the medicine is the magic answer to his problems.

She was the first one on Clozaril in this county. And so far its worked good for her. It has never gotten her to where we’d like her to be, especially with the voices. But she seems happier and she seems to have adjusted to her life.

He was doing very well. And he had the same psychiatrist for about 16 years. And this doctor retired, and his medication was changed. But no medicine agreed with him. And we started to experience difficulties with him at home. He’s been trying different medications and nothing seemed to work. Nothing worked like it did before.

About 2 years ago, he seemed to be on a good dosage of medication they gave him and he was very much normal and like he should be and it was such a pleasure to have him that way. But then again he’ll, which is very common, he’ll refuse to take medication, and then it gets very bad.
Mental Health Professionals and Services

One of the biggest influences I see in her life is attending the clubhouse, and I just can’t tell you enough wonderful things about them.

He used to be so angry, he’s not like that since he’s going to the community support program. The anger has really calmed down a lot. I do appreciate them and the time they spend with him because it gives me a little more time.

He’s had a lot of help from social services, which has been a blessing because I don’t know where he’d be if he hadn’t had help.

We got him into a community program, and that was really good for him. He got along there, they had classes, they did things, they took him on outings, ... and lots of things that these people did not have otherwise. Then the agency cut the funding. It left all of these people with nothing to do.

I could see the symptoms coming back so I talked to her case worker and told her this, but she didn’t do anything right away. My other two daughters kept calling her (case manager) on the phone and saying something has to be done and nothing was done. I could see her symptoms coming back but I couldn’t do anything about it.

I tried to get him an evaluation and the school psychologist kept saying that histrionics was his problem–that he was having physical complaints and these were being exaggerated because of his fears. And that was a frustrating period because I couldn’t get the help that I felt he needed. He was having serious problems and everyone kept telling me that I was exaggerating and I was over-anxious and that I was just spoiling him.

I made 100 calls trying to get help for him because he didn’t have health insurance. And finally I met some very nice, kind professionals in the mental health field.

She’s feeling badly that the clinical services are telling her that she shouldn’t be in touch with us as much as she is. Our feeling is that as long as we’re here, we intend to help her out as much as we can.
Advice from Consumers

Praying to a higher power. Praying and talking to God helps me.

Learning to be your own best friend and being your own problem solver.

Writing your feelings on a piece of paper. Art, creative expression through art, drawing, painting helps a lot.

Talk to your doctor. Once a problem is mentioned, it doesn’t seem so serious. Talking about things helps put them into perspective.

Keep busy around the house, doing chores, talking to people, being someone’s friend. Get some exercise. Go for a walk, lift weights, play volleyball.

Talking to friends and family about daily routine and its ups and downs helps a lot. I live alone. Having someone to talk to helps a lot.

Take a deep breath before you speak. I can avoid apologies by thinking about how I’ll respond first.

Taking your medication.

Taking quiet time, listen to music, learn to meditate, watch T.V.

Make and keep a schedule. I accept the consequences if I’m not doing what needs to be done.

Remain hopeful about the future. Every day is a new day and there will be some good days in there.

It helps a great deal when your parents are involved and supportive. If you don’t have parents, adopt a grandparent to talk to and relate to. The older folks really know what they are talking about.

Heal relationships with your family. It was the best choice I made. Choosing to work on those relationships was the basis for improving my life.
**Concerns About the Future**

**From Mothers . . .**

He cannot seem to get over being locked up and now being back in the community. He’s afraid of everything. He’s afraid of meeting people because of his lack of education. He can’t quite comprehend everything that’s going on. That’s the worry I have. I’m older now and I don’t know what will happen. He has often told me that when I die, he’ll kill himself.

He has a sibling that only lives a couple blocks from him. I can see her kinda taking him under her wing, and I have this feeling that he will be taken care of when I can't take care of him anymore.

One of my greatest fears is that he won’t get the medical care and that he’ll die on the street...

He loves his sisters and brother, but they couldn’t handle living with him. And they can’t handle when he’s having episodes, because they’re afraid he might get violent.

I’m trying to get her to realize that I’m not going to be here forever. And I’m trying to get her to be more dependent on her social workers and get them to do things for her and with her, which we actually haven’t been too successful with.

I’m very concerned about what will happen to him when I’m not longer able to take care of him. I hope that he will be able to move out on his own, and establish some independence before that happens. But I know that he’s going to need support. I can’t visualize him coming to a point in his life where he no longer needs support.

I am gonna be 65 this next year. I don’t know what’s gonna happen to her if I pass away. I have a very big concern on that. What’s gonna happen to her? When I would talk to her sometimes about this, she would say, “Oh, I’ll just move in with my brother.” I say, “No, you got to learn to live on your own. They have their own problems.” And she once in a while will discuss with me the possibly of finding an apartment of her own, but the problem is the money. She can’t really handle it.... And could she ever find an apartment that is safe, because of her being a low-income person? That’s a big concern, is a safe, a safe place to live.
The older we get the harder it is for us and, I think, the harder it is for him because he’s very aware that we’re getting older and what is he going to do. And I hear that sometimes. I think that he is afraid when we travel because he is afraid that something will happen to us. And I think, knowing him well enough now and the illness, I think he’s afraid of what will happen to us because then what will happen to him.

And again, I can understand his need for being independent, because I’m afraid of what’s going to happen if I pass away or something happens to me. How is he going to make it in this world? And we talk about that a great deal too, because it does bother him too. It’s like what are we going to do if something happens to you? Who am I going to turn to for help?

We have a daughter that just got married. Her husband works with the mentally ill. And he has always said that, when they got married, that if anything ever did happen, that he would step in and take over.

**From Fathers . . .**

I do not want to burden my other children. I fear that my other daughter will find that she will have to take on the caregiving role.

He is so dependent on us that I fear he may fall apart and end up in an unloving environment.

We are her life. My older daughter says that she would look after her, but she lives in another state, and our daughter is happiest in Wisconsin with familiar surroundings.

Where will she live? How much financial support will she need? Who will be her friends? Who will fight her day-to-day battles with the insurance companies, the bank, social security?
Advice to Other Parents

From Mothers . .

Do the best that you can and don't judge yourself. It’s an uncontrollable situation. The only way that you can get through it is by practicing unconditional love. Parents really need to forget about themselves because schizophrenia is an illness of self-absorption. You can't have any expectations of this person.

Don't blame yourself. Accept the fact that there is nothing you can control over the illness. Support your child with whatever comes up.

Probably the biggest help for me was I took this course, they call it now Family-to-Family, offered by the National Alliance for the Mentally Ill.

Find a social worker to work with. It’s easy to get good direction from a social worker. Be sure to take little steps in the healing process.

Being with a group of people who are facing the same kinds of problems and have them listen as you go through the grieving process of the loss of the person you had before.

Don't keep it to yourself. Talk to people about it. Don't be embarrassed about it; it’s like having a family member with cancer, diabetes, anything else.

Going to his doctor's appointments and group meetings with him.

Maintaining outside interests so you can get away from it. Don’t blame yourself for his condition.

I got away and went on trips. I felt guilty at first, but I needed to get away and deal with this. I had to make the time for myself, otherwise it would've devoured me.

Take care of yourself first. Hang onto your hobbies, interests, and friends. Become active in advocacy for treatment of mental illness and especially join a National Alliance for the Mentally Ill group. Above all, never give up hope.

Realizing that she is very ill and that her behavior is typical of her illness, that the child is suffering more than you are.
The book *Surviving Schizophrenia* helped. Coming to the realization that this illness is permanent and accept it. You can't hide it and cover it up. You are living a lie if you don't become yourself again. Be open and don't hide it.

I really recommend a spiritual attitude about life. Prayer will alleviate a lot of fear and you'll learn to appreciate the positive aspects of what an illness such as this can bring to your life.

It's just so hard when something like this happens. All of a sudden, you're seeing such a different kid. You never get used to it.

Learned to rejoice in the good days. You have dreams for your child when they're young and if they die of a physical illness, you learn to grieve and go on, but when a child gets this illness, you don't seem to be able to cope as well. The grief doesn't go away.

It's been a difficult road, but it's a lot easier now. I always had hope. But deep down, I didn't think it would be this good. It's really good. I'm very thankful. I wish I could tell families going through this not to give up hope. You get in a roller coaster situation that at some point you want to throw your hands up. I wish I could tell them there's hope, and they can get better. Hang in there, it's worth it.

**From Fathers . . .**

Learn all you can about the illness. Take a Family-to-Family class offered by the Alliance for the Mentally Ill. Join a support group and be patient with your son or daughter. Progress is very slow.

Let your son or daughter know that you will always be there for them. Tell them that you love them, give them a hug, and when they need professional help, help them get it.

Don’t spend your life beating yourself up over it or trying to cure or “fix” the problem. Mental illness is a brain chemistry problem; you did not cause it.

Search out others who have been through this problem.

Share the problems with your wife and your family, and support one another.

Understand that this illness is beyond any one’s control.