As with the acquisition of most skills, learning to cope with a disability is a function of experience and guidance from others. The author, diagnosed with schizophrenia at age 25, is now a psychologist who works with persons hospitalized with mental illness. He has frequently delivered presentations about coping with schizophrenia during the past 3 years. His ideas are based on his personal experience of living with the disorder, his experience with his patients, and that which “rings true” to his thoughts on twelve aspects of learning to live with this serious mental disorder.

When people lie, sparks are set off in the brain, thus melting brain chemicals which may be the conscience and pride. “I was 2 years old when I got my doctorate, an M.D. from Harvard. I got a Ph.D. in comparative literature and a law degree at the same time, as well as a phi beta kappa in care-giving from Sunny Acres.”

The above is a paraphrased sample of speech from one of my actively psychotic schizophrenic friends. She is really a very nice person and has a lot of good ideas, but obviously something is not quite right with the way she is thinking.

I, too, am a person with schizophrenia. I am not currently psychotic but I have been in the state of psychosis frequently enough to have become somewhat familiar with the trips there and back.

After years of keeping my experiences with schizophrenia a secret, a few years ago I decided to become open about my condition. Initially I revealed my background during talks I was giving locally. Later, at the invitation of various groups of professionals, consumer/survivors and family members, I began giving talks around the country. At first I gave a talk calling for partnership between consumer/survivors, professionals, and family members. The speech was fairly well received. But at the annual convention of the South Dakota Alliance for the Mentally Ill, I was asked to give two different speeches to the same audience. I decided to give the second speech on coping skills. In doing so I learned consumers and family members would far more like to hear about how to go about living with schizophrenia than about more theoretical or political aspects of caring for the mentally ill.

My first speech in South Dakota was given almost 3 years ago. Since then I have given the same basic talk several dozen times in about half the states. The speech has evolved considerably since it was first delivered, as audience members contributed comments that I felt were particularly valuable.

My talk addresses twelve aspects of coping with schizophrenia. I have organized it a little differently for this article, but I still keep the basic twelve aspects as the organizational framework for the presentation. What follows is the essence of the basic speech, adapted for publication.

1) Denial, Acceptance, and One’s Belief Structure

I cannot tell you how difficult it is for a person to accept the fact that he or she is schizophrenic. Since the time when we were
very young we have all been conditioned to accept that if something is crazy or insane, its worth to us is automatically dismissed. We live in a world that is held together by rational connections. That which is logical or reasonable is acceptable. That which is not reasonable is not acceptable.

The nature of this disorder is that it effects the chemistry that controls your cognitive processes. It affects your belief system. It fools you into believing that what you are thinking or what you believe is true and correct, when others can usually tell that your thinking processes are not functioning well.

I had been hospitalized five times before I was willing to consider the possibility that there might be something wrong with me. We are all conditioned from birth not to accept that which is crazy or insane. That which is insane is beyond the pale of that which those in our human family will accept. We accept that which is logical, that which is rational and reasonable. That which is crazy is dismissed. Therefore it is very difficult for us to accept that what we are thinking is in fact crazy. Psychosis is a “catch 22.” If you understand that you are insane then you are thinking properly and are therefore not insane. You can only be psychotic if in fact you believe that you are not. Therefore almost everyone with this disorder initially denies that they have it. Some deny it all their lives. Most of the 300 patients I have in the hospital where I work will tell you that they are not mentally ill. Denial of the disorder comes as part of the territory for most of us who have it. Some of those who have the disorder not only deny that they have it but also deny that it exists.

It is exceedingly difficult for you to admit to yourself that your mind does not function properly. It fools you. With this disorder you develop an epistemological structure that is not consonant with that of the vast majority of those in the larger, majority population.

But if one does not acknowledge that they have the disorder, how can it be helped? Why would anyone want to be cured of a disorder that they do not believe they have?

I find that a good approach for persons in such denial is to point out that, even though they may not have the disorder, it is true that they have been treated by others as though they do have mental illness. They will usually agree with this thesis, especially if they have been hospitalized. Often these folks will accept being referred to with a term like, “survivor.” Once they have accepted the fact that others may view them as mentally ill, they then have some motivation to learn more about the disorder.

It is generally best not to try to make a “frontal assault” against denial. Try to establish a trusting relationship and gradually chip away or “defreeze” the rigid cognitive defensive structure that constitutes the denial.

2.) Knowledge of the Disorder

In this, the “Decade of the Brain,” evidence continues to mount that viewed from an objective, or scientific perspective, schizophrenia is a brain-based disorder. It can be best conceptualized as an imbalance in the biochemistry of the brain’s neurotransmitting systems (Gershon & Rieder, 1992; Wong et al., 1986). Studies are published with great frequency now, further establishing the neurophysiological correlates and consequences of serious mental illness. As articulated by one prominent psychiatrist, “Patients have to be taught to accept the fact that they are ill, that this is not a mystical experience but a disease—an illness that needs treatment.” (Canaco, 1992).

From the viewpoint of the person with the disorder, however, the phenomenon can be very much like a mystical experience. The young psychiatrist, Carol North (1987), describes herself as being in a parallel reality or at a cosmic juncture. I (Kraemper, 1993) have referred to one of my breakdowns as “cruising the cosmos.” David Zelt (1981) describes himself as being “constantly in touch with the infinite and the eternal.”

The nature of the disorder is that it affects the brain’s thought and belief systems, it affects a person’s confidence in what is truthful. Therefore, to the person who is experiencing the disorder it very much can be a mystical journey where poetic relationships and metaphorical associations dictate truth. To the person who is experiencing the disorder, these subjective experiences are very real indeed.

Therefore, while one should try to understand as much as possible about how the disorder is accompanied by biochemical irregularities, one should also understand that for the person who has the schizophrenia, it indeed can be a mystical or even a religious experience.

Often these mystical experiences can be most seductive. One has the feeling that he is having special insights and even special powers. One is no longer restricted by the rigid control of rationality. One begins engaging in what experts have called paleologic (Arieti & Brody, 1974) or parataxic thinking (Sullivan, 1953). Many consumers/survivors prefer the term, “poetic” logic.

B

Because our disability is one of a biochemical imbalance, it is reasonable that our “crutch” is chemical. For us, our crutch is the neuroleptic medications that we take.

3.) Medication, Chemicals

Persons with serious mental illness are disabled, just like people who are blind, deaf or crippled. Like others who are disabled we can be helped by artificial support. Where the blind may have a cane or a seeing eye dog, the deaf may be helped with a hearing aid, and the crippled may be helped with a wheelchair or a crutch, we, too, can be helped by artificial means. Because our disability is one of a biochemical imbalance, it is reasonable that our “crutch” is chemical. For us, our crutch is the neuroleptic medications that we take. In order to keep our brain’s neurochemical processes properly balanced, we need the assistance of helpful chemicals, prescribed medications. Certainly without having such medications available, I would not be able to function as I do today. True, there are side effects of these drugs: akathisia, akinesia, dyskinesia, dystonia, et cetera, and these can be quite problematic, even disabling. But the medications are becoming better. Around the country I have met dozens of persons who have been helped by clozapine, which has only been widely available in this country for a relatively short time. The drugs Risperidone, Fozidom, and Olanzapine, which may be widely available during the next few years hold out further hope for those of us who are disabled with mental illness. Those of us who are dependent on these drugs should attempt to learn all we can about them and their side effects, both short term and long term. These medications hold
such hope for us. But just as some chemicals function to assist us, others are harmful to us. Such “street drugs” as PCP and amphetamines are much more likely to cause a recovered schizophrenic to relapse into psychosis than they are to have a similar effect on a “normal” individual. Likewise, marijuana and alcohol also increase the likelihood that persons with these vulnerabilities are going to experience mental breakdowns. Those of us with these vulnerabilities to breakdowns in our biochemical systems need to learn as much as possible about the effects of drugs so that we can utilize and avoid them in a judicious manner.

4.) “Paleologic” or Delusional Thinking

When a healthy individual functions in a normal manner, encountering moderate degrees of stress and pressure, his or her physiological systems operate in a healthy manner. But when stress increases and is sustained, physiological systems begin to wear and weaken. Eventually they malfunction. They break.

Different individuals react in different ways. Some people react more with blood pressure increases, others more readily with sweaty palms. Still others react with increased gastrointestinal activity, their stomachs churning. Psychopneurologists refer to this as “response specificity,” and point out that people tend to develop symptoms in the physiological systems in which they are most reactive (Sternbach, 1966). Blood pressure rises when we are moved to tears by a story or to laughter by a joke. But we rapidly recover control and are guided by rationality. We remain confident that that which is reasonable or logical is true. We can believe that which strikes us as rational.

But when our rational processes break down, our cognitions become dominated by the activities of the paleocortex. Our mental processes begin to become dominated by paleologic (Arieti & Brody, 1974) activity. We begin to lose our confidence in rational processing and begin to see truth in nonlinear relationships.

5.) Social Deficits

Miller and Flack (1990) presented an interesting paper recently. In observing schizophrenics in social interaction and comparing us with normals, they found that we tend not to look at the person to whom we are talking. From our perspective, there is good reason for this, of course. We are even more distracted and if we look at others while we are talking we will see their facial reactions, making it more difficult to focus on what we are saying. This naturally can be most disconcerting to the person with whom we are conversing. Normals expect signs of interaction when they are speaking with others. Since we often fail to respond in the expected manner, we throw them off.

Miller and Flack also point out that compared to normals we schizophrenics are much less likely than normals to nod in agreement or move our hands in rhythm with our partner’s speech. Often when we do nod appropriately it will be later in the course of talking than is usually expected. The reason for such delaying is that we spend a longer time processing information than normals. Such delays of course tend to throw off the rhythms of a conversation. Normals find this disconcerting. They often do not realize that our failure to send and receive the expected cues during conversation is part of our disability.

Normals send other signals in conversational encounters. They use short statements at the beginning and end “How are you?” or “See you Wednesday” and longer statements in the middle. They also lower the pitch of their voice to indicate they are finished. Schizophrenics tend not to do this. We seem to have a defect in our cue signalling mechanisms. As a result we often have difficulty in knowing when we should be ending a conversation or how to do it. Miller and Flack feel we are defective in our capacity to engage in shared communicational activities. I would agree but I feel if we know the nature of these defects and those with whom we come in frequent contact know about these deficits, we can better work together to overcome them.

Others (Lysaker, Bell, Milstein, Goul, & Bryson, 1993) have reported that schizophrenics’ deficits in social communication skills interfere with their functioning in vocational settings. They point out that schizophrenics may perceive a joke as a threat, or otherwise misunderstand communications by coworkers and employers. Often persons with schizophrenia can perform the work as well as normals, but due to their deficits in social and communication skills they have more difficulty in the work setting, often to the point of even losing their employment.

Clearly, those of us with schizophrenia need to know more about our deficits and those who frequently interact with us need to know about our deficits in social interaction. Together we can work to better compensate for them.

6.) Replaying/Rehearsing

Often when you visit a psychiatric hospital you will see patients who seem to be talking to people who are not there. In their one-sided conversations they will often become quite animated. Because they are talking to people who are not there, it is usually assumed that they must be hearing voices and talking back to them. Although this may sometimes be the case, often something quite different is at play.

Those of us with schizophrenia are very sensitive to having our feelings hurt. Insults, hostile criticism, and other forms of psychological assault wound us deeply, and we bear scars from these attacks to a much greater degree than do our normal friends.
Because we have this hypersensitivity, naturally enough we try to protect ourselves and prepare ourselves from possible future attacks. By way of this, one of the things we do is replay in our minds situations where we have been hurt, trying to develop strategies of response so that if we find ourselves in similar situations again we will not be so damaged again. What we are doing in our minds is saying to ourselves, "What I should have said was..." or "I should have told that guy that I am just as good as he is." We rehearse or replay situations over and over in our minds, and we often find ourselves speaking in an audible fashion when we are doing this. We have a definite compulsion to engage in this sort of behavior.

Many years ago my wife became so bothered by my tendency to do this, that we worked out an agreement that I would try to engage in this behavior only when I was in the shower in the morning and while I was mowing the lawn. The lawn mower motor tended to drown out the sound of my mumbling.

Persons with schizophrenia need to know that we have this tendency to talk to ourselves and that this behavior tends to upset normals. I recommend that whenever we have a need to do this that we do the same thing that we do when we have other physiologically based needs to function in a manner not welcome in polite social circumstances. We should excuse ourselves, withdraw to a restroom, or other area where we can be in private and rehearse/replay until we get the urge to do so out of our system.

Despite this advice, I frequently find myself in social situations where I am talking to myself, usually in a soft tone. It is at times like these that I am most grateful that others know that I am disabled with schizophrenia. Because of this I think others expect me to be a little different. So when they see me talking to myself they do not seem to be quite so perplexed.

7.) Expressed Emotion

The Expressed Emotion (EE) concept was developed by George Brown and his associates in the Institute of Psychiatry in London in the 1950s (Brown, Carstairs, & Topping, 1958). Brown's studies focused on the relationship between family variables and the likelihood of relapse on the part of persons with schizophrenia who had recently been discharged from the hospital. Those investigators found that patients who went to live with family members who were highly emotionally involved were much more likely to relapse than those patients who went to families who were less "hostile," or who exhibited less "expressed emotion." Furthermore, the relationship between emotional involvement and relapse was not related to the severity of symptoms at the time of discharge.

High EE was defined as involving three factors. These are from the Camberwell Family Interview (Brown & Rutter, 1966):

1.) Statements of resentment, disapproval, or dislike, and any comments expressed with critical intonation that is, a critical tone, pitch, rhythm, or intensity in their voice.
2.) Hostile remarks indicating personal criticism.
3.) Emotional overinvolvement, constant worrying about minor matters, overprotective attitudes, intrusive behavior.

Additionally, warmth, expressed in terms of positive comments and voice tone, appear to be added protection for persons discharged to low-EE environments and dissatisfaction, even when not expressed in a critical or hostile manner, appeared to increase relapse risk in high-EE households.

It is my experience that those of us with schizophrenia are indeed very sensitive to hostile criticism and other forms of expressed emotion. But it is not only in the family context. Whenever persons with schizophrenia encounter criticism, insults, or other forms of psychological oppression, we tend to be damaged in a manner that increases the likelihood of our relapsing into psychosis. This vulnerability tends to be part of the disorder. Those who have this disorder need to know that they are vulnerable in this manner. Other persons who come into frequent contact with the mentally ill also need to know that we are particularly sensitive in this regard.

As with those in the AA organization, those of us with schizophrenia need to avoid the persons, places, and things where we are likely to encounter expressed emotion. But of course, we will not always be able to avoid such circumstances. For those times when we are going to encounter hostile criticism, etc., I recommend that we be prepared to protect ourselves by developing a mechanism for communicating to others something about the nature of our disability. Some years ago I developed a card which I carry in my wallet. When I find myself being faced with unfair criticism I will present the person doing the criticizing with my card, which has these words written on it:

Excuse me. I need to tell you that I am a person suffering from a mental disorder. When I am belittled, insulted, or otherwise treated in an oppressive manner I tend to become emotionally ill. Could I ask that you restate your concern in a manner that does not tend to disable me? Thank you for your consideration.

While I don't use this card frequently, I do find it gives me assurance to have it with me.

8.) Stress and Excitement

Not long ago three former patients at our hospital were the focus of a local TV news program on mental illness. All three performed very well for the program but unfortunately within 3 weeks each of them had relapsed and were back in the hospital. My own breakdowns frequently occur while I am attending conferences or shortly thereafter. I often find that visits to a shopping mall where there is much stimulation causes me too much stress.

Persons with schizophrenia should realize that they can become overstimulated by exciting circumstances as well as by stressful circumstances. We need to develop techniques to limit the effects that overstimulation may have on our systems. I find that when I begin to become overstimulated it is often helpful to politely excuse myself and withdraw from the situation. If I am at a conference I can withdraw to my room or if I am at a mall I can withdraw to a less stimulating environment.

I find that if I know ahead of time that I am going to be in a stressful or exciting situation for an extended period of time it is helpful to increase the dosage of my medication prior to involving myself in such events.

At meetings where there are often sharp exchanges between the participants, I find that it is helpful to withdraw from the circle of participants and sit at a distance from the verbal exchanges. It is less taxing to be out of the line of verbal fire that often occurs during meetings where important issues are being discussed.

9.) Music and Hobbies/ Woodshedding

Because the nature of our disorder is such that our ability to sustain our rational processes is damaged, it is often helpful if we engage in activities that do not tax our logical abilities. Music, art, and poetic type endeavors are often easier for us to handle. For this reason I encourage persons disabled with schizophrenia to engage in these forms of expression as a way of communicating.
10. Stigma/Discrimination

Traditionally those of us who were struck with mental illness were ejected from society and placed in isolated asylums. The words “crazy,” “insane,” and “nuts” have come to mean those things that can be immediately dismissed as unimportant by the members of the normal population. Until about 30 years ago those of us who were determined to be insane were removed and not expected to return to society. When we did start returning we were not generally welcomed. As I pointed out in a recent article (Frees, 1993b), the movies have a tradition of portraying the mentally ill as monsters. The news media also primarily addresses mental illness when one of us has killed or has committed some other form of bizarre crime.

While normals can speak openly and even casually about cancer or heart disease, the topic of schizophrenia elicits primarily emotional reactions like fear or derisive humor. Normals are not comfortable with the thought of a seriously mentally ill person living in their neighborhood, being in school with them, or being in their workplace. We still frighten them. They do not know what to expect from us.

Recently the National Mental Health Consumer’s Association adopted a six-part national agenda. One of that organization’s six designated issues is discrimination, for which the following is stated, “Discrimination, abuse, ostracism, stigmatization and other forms of social prejudice must be identified and vigorously opposed at every opportunity.” Likewise there has been established a National Stigma Clearing-

house (275 Seventh Ave., 16th Floor, New York, NY 10001) which monitors and challenges media stereotypes of the mentally ill.

For those of us who have returned and have found that we are not as welcome as we would like to be, we have a challenge.

We must work together to change the image we have with those in what I sometimes refer to as the “chronically normal community.” As more and more of us are becoming open about the nature of our disability, we have an obligation to share with others as much as we can about mental illness so that there is less fear and greater understanding and acceptance. To help counter the negative images, it is of course helpful to have positive images of the mentally ill to put forth. Mike Jaffe (1993) and his family have done us all an outstanding service by producing and widely distributing posters highlighting “people with mental illness (who) enrich our lives.” They point out that such persons as Robert Schuman, the composer, Vaslov Nijinski, the dancer, Eugene O’Neill, the playwright and many other accomplished individuals, suffered from serious mental illness.

Of course I cannot leave the topic of discrimination without mentioning the Americans with Disabilities Act (ADA). This recent legislation is seen as a significant step forward for us in the area of employment opportunities, building on legislation that has been evolving during the past two decades.

Numerous consumer/survivor activists have stated that the stigma that accompanies serious mental illness in many ways is worse than the illness itself.

11. Revealing/Covering

Since deciding to become open, and even public, about my condition, I have received quite a bit of media coverage. One consequence of this is that recovered mentally ill persons, including many professionals, who

have not been open about their condition, contact me and ask if it is wise to share such information with others, particularly their employers. Some time ago I developed a strategy for approaching others such as employers.

The consumer/employee takes an article about myself or another recovered person and shows it to the boss. If the boss’s reaction is positive, saying something like, “That person must be very brave and is probably making a real contribution,” then you know it may be safe to share with him or her about your own background.

If, on the other hand, the boss’s reaction is more along the lines of, “I’m sure glad we don’t have a ‘nut case’ like that working here,” then you might want to be a little more cautious. Interestingly enough, those who have tried this strategy in mental health settings have received both types of reaction. Those who receive a positive reaction generally follow up and reveal that they, too, are recovered persons. Usually this is a therapeutic relief for them. It is very difficult to carry a “shameful” secret with you. When we consumers meet at conventions and elsewhere I often hear statements like, “I am so tired of hiding,” from those who are not open to others about their condition.

However, as a practical matter, many persons probably should not be too open about their past. The ADA affords some protection and even advantage to officially stating that you have a disability but there is still much discrimination.

If you decide not to reveal to others, how do you cover for the time you were in the hospital? If you are unemployed how do you answer when asked what you do for a living? Many consumers find these very difficult questions to handle.

I advise that you respond by saying you are a writer, an artist, a (mental health) consultant, or perhaps that you “free lance,” depending on how you have been spending your time. None of these respons-

As Tim Woodman (1987) relates in describing his disorder, “What really helped was art therapy. I got a lot of satisfaction out of painting, and it seemed to me to go some way toward answering my unspoken desire for personal harmony” (p. 330).

In my own case I find that dancing for extended periods of time can be very therapeutic. There is something about being able to express yourself in a nonrational manner that helps release pressures that have built up from stresses that have been encountered. Often these musical or artistic expressions come forth in a manner that is not readily appreciated by others.

Nevertheless, the fact that we are expressing ourselves can be most therapeutic. A term that has been adopted for such activity is “woodshedding.” (J. Strauss, personal communication, December 17, 1990.) This term is used to mean jazz, where a musician will go out away from others to a woodshed and experiment with various sounds until the sounds begin to form patterns that can be appreciated by others. For those of us with schizophrenia, engaging in woodshedding activities, whether they be in art, music, or poetry, can be a viable method for building a bridge back to the world of normality.

Not long ago a patient of mine who engages frequently in writing poetry wrote a poem that I feel carried a particularly insightful message to mental health workers. She wrote:

Be my teacher
Not a preacher,
And as I learn,
Give me a turn.
es are lies, per se, but they leave considerable latitude for interpretation and they do not require that you have a specific employer or work location.

Whether you decide to reveal or not is a serious personal decision. If you are older, established in a career, particularly in the mental health field, it is probably safer to become open about your condition. Obviously, the closer you are to retirement age the better. But if you are younger, just starting out, you might want to be very careful about becoming too open about being a person with serious mental illness. One important thing to remember is that once you tell others about yourself, you cannot untell them. Once you become open, there will be insults, subtle and otherwise. If you decide to reveal, be prepared to do a lot of educating of our "chronically normal" friends.

12.) Networking/Consumer Groups/ Self-help

Whenever I was released after being hospitalized, I always knew that there were others who were like me, those who had received psychiatric inpatient treatment and were now in the community. But I had no way of knowing who these people were. Everything was clouded in secrecy. There was no practical way for one to meet others who had similar experiences. As a result, being a recovering mentally ill person was a very lonely experience. As I did, too many discharged persons spend too much time alone in a room watching television or just looking at walls.

Fortunately this situation is changing. Fourteen years ago the National Alliance for the Mentally Ill (NAMI) was founded and regular meetings of family members now occur in virtually all of the states and larger cities in the country and in many smaller ones. Many of these groups encourage involvement of recovering persons themselves as well as family members. Indeed, NAMI has a national network of recovered persons called the Consumer Council. Recently members of this network have been gaining more influence within NAMI and as of this writing they occupy three positions on the NAMI Board of Directors.

In addition to the consumers active with the NAMI organization there are two independent national consumer organizations which are active in networking and advocating for recovered persons. The National Association of Psychiatric Survivors (NAPS) is active in advocating for the rights of consumers, but takes a position in opposition to any form of forced treatment, a stance that some recovered persons are not comfortable with.¹

The third nationally active organization for recovered persons which has been regularly recognized in discussions of public policy involving the mentally ill is the National Mental Health Consumers' Association (NMHCA)² This organization is also independent and it has traditionally taken no formal position concerning the forced treatment issue.

All three organizations have been active in articulating news of persons who have received treatment for serious mental illness. Depending on one's degree of comfort with the family movement and feelings about the forced treatment issue, the activities of one or more of these groups could be of interest to recovered persons wanting to become more active in advocating for bettering conditions for persons with mental illness.

In addition to these national groups, most cities and states have consumer organizations with which one can affiliate. It has been my experience that recovering persons benefit greatly from associating with others with similar disabilities.

In some areas consumers have taken the initiative to establish facilities for recovering persons that are operated by themselves. They may or may not work in concert with traditional mental health providers, but control of these operations remains in the hands of recovered persons themselves. These are usually referred to as self-help efforts and are generally found to be cost effective and much appreciated by the consumers who are involved with them. Indeed, recently when the board members of the NMHCA organization were asked to identify their highest priority in restructuring the delivery of mental health care in this country, they unanimously identified self-help as their major issue. With this kind of enthusiastic support, it is likely that self-help consumer-run drop-in centers, social clubs, and crisis facilities will become more widely available.

References


¹ The NAPS organization went out of existence in 1995.

² NMHCA is theoretically functioning but does not have a working address.


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