

Now That We Are Listening

Psychiatrists Report on Letters to *Dear Abby* from
People with Schizophrenia

**Committee on
Psychiatry and the Community**

Group for the Advancement of Psychiatry
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PREFACE

Some time ago our committee of psychiatrists at the Group for Advancement of Psychiatry (GAP) approached Dear Abby about placing an item in her column requesting that people diagnosed as having schizophrenia write in to describe their experiences with psychiatrists and psychiatric treatment. This publication summarizes what we learned from the letters we received. Although our project was not a scientific study of a representative sample of people with schizophrenia, we believe that the voices of our writers offer a unique perspective on the experience of managing a painful mental illness.

Dear Abby,

I was horrified after my first hospitalization. I had always been a model student, never particularly rebelled. I completed college, held jobs and now something had happened which I did not understand. At any moment, I felt, my life might once more spin out of control. I didn't have a clue what to do to help myself.

So begins one of the more than 500 letters we received. Here is another:

The help I got from psychiatrists was in the area of diagnosis and medication. That was useful, but it did not give me any coping skills. I happened to be lucky to develop coping skills through group therapy and creative behavior classes. I also learned through my reading in human potential literature and spiritually oriented books.

We need to be told we are valuable human beings, lovable people with a capacity for love and giving of ourselves. Our own nightmarish thoughts drive our self-respect and self-love and self-trust out of us. Sometimes we need to be taken by the hand and walked through a simple decision just to learn how to discriminate what is good decision-making and what is bad. I know schizophrenics can be helpful to others.

We talk among ourselves about the different qualities of our psychiatrists. Sometimes we feel

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“listened to” and sometimes not. Doctors have the upper hand in the interaction. Often we, the patients, feel we have to alter the truth out of fear of what the doctors will do. We do not feel we can be honest. They hold power over us in their ability to give or take away medication and other treatment. If medication were impossible to get I would probably commit suicide to avoid the tortures of my own mind. They should accept this power with humility, believing they are only tools in the overall Scheme of Things and that they are not more valuable than anybody else.

Of course, not every doctor and every patient are a good working team. We, with our impaired ability to discriminate, sometimes need more honesty from the doctors. They sometimes need to be the ones to say they can't work with a certain patient, because the patient is not in a position to do the choosing. I have had a doctor leave me and I respect him for it. When he left I was able to get better service from another doctor.

The writer continues:

I think many schizophrenics fall through the cracks in our system and do not develop their potential because the mental health system does not provide adequate information. This is a big issue to me. I believe if I had been told in the hospital more about the positive and negative effects the medication could have on me and about the doc-

tor's plan to eventually reduce my dosage, I would have been more receptive and cooperative.

I believe doctors need to realize that we need to grieve a great deal. We need to grieve the loss of normal lives, normal families, normal places in society. For me this is a continuous process that never ends. We are placed at the very lowest rung on the ladder of society. We are believed by many to be ax-murdering fiends—all of us, even though statistics do not bear this notion out. Doctors need to see that we don't take all this lightly. We get depressed because we are labeled schizophrenic. We also feel angry toward Fate, or our families, or ourselves. Not only do we have an illness, we are condemned by society and often by ourselves, too.

As to the success or failure of my treatment—it has been successful. Recognizing there is no cure for schizophrenia, the doctors, nurses, and occupational therapists and I have made the best of it. Without them I would probably be dead or chained in a basement somewhere! So, I repeat, I am thankful.....for psychiatrists.

This author makes it especially clear that when her treatment was flawed and insensitive (as it sometimes was), she felt injured and demeaned. When it was thoughtful and respectful, she was able to move toward recovery and was pleased and grateful. Like many who responded to Dear Abby's request, she wrote at length on the importance of

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being listened to, emphasizing the need to address patients candidly and to educate them. She pleads with psychiatrists to recognize their patients' sufferings, fears, and grief. Most important, she emphasizes the need to be dealt with as a valuable person, a feeling and thinking human being, and not merely as "a patient" or "a schizophrenic."

The letter covers many of the issues we wanted to hear about when we made our request for letters from patients for a project being conducted by our group of psychiatrists, The Committee on Psychiatry and the Community, which is a component of the Group for the Advancement of Psychiatry. Our report summarizes what these people told us about their perspectives on the treatment of serious and persistent mental illness. We quote from the letters with some minor editing for brevity and clarity, and we have deleted the names of people and programs to preserve anonymity, but otherwise we present the excerpts just as they were written.

As we began the project, we had several questions: What will people tell us about their experiences of psychiatric illness and treatment? What can we learn from their stories and how can these lessons be used to improve mental health care?

But there was a larger question that plagued us right from the start: How useful would these letters be? We didn't know what to expect. For a previous report, ("A Family Affair")¹ our committee had solicited letters to Dear Abby from family members of people with mental illness concerning the treatment of their relatives' illnesses by psychiatrists.

We received over 500 letters, many of them heart-

rending and powerfully written, many of them indicting mental health professionals for failure to be appropriately responsive. Though sometimes less emotionally evocative than the letters from family members, letters from patients consistently impressed us with their dignity, wisdom, courage, and spirit. Reading them reminded us of how articulate people with schizophrenia can be. We understood we were not conducting a scientific study nor verifying the writers' diagnoses. We cannot say what percentage of people with schizophrenia who read Dear Abby's column responded by writing a letter, nor whether those who wrote to us were more likely to have experienced greater recovery than those who did not. It is possible that readers with the strongest feelings about psychiatrists, whether positive or negative, were more likely to respond. Every sample is skewed, whether it involves people who agree to participate in a research study or those who choose to write to Dear Abby. For all of us, it was certainly illuminating to hear from writers we might not meet in our own practices.

The opening letters are characteristic of many of the letters we received, which were remarkable for their intelligence, clarity, thoughtfulness, and intensity. As a whole, the letters gave the impression that there were a great many mental health "consumers" waiting for a chance to be heard, to express strong feelings, positive and negative, about their dealings with the "treatment system," and with their psychiatrists in particular.

OUR REACTIONS

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As psychiatrists, we are used to “listening” to “patients,” but the letters to Dear Abby captured our attention in a very different way. These were not “patients” seeking our help, but people—people with mental illness to be sure, but individuals first—who were talking to a third party about our profession and about mental health treatment in general. We were repeatedly struck by the incisive—and, for us, often humbling—assessment of the relative value of our profession in helping them to recover. As the author above notes, she is “thankful for psychiatrists,” but the help she got (“diagnosis and medication”) was merely, “useful.” It did not give her “coping skills.” We found ourselves listening to what the letters had to say without the ability to “do something” to “fix the problem.” This was uncomfortable, but it helped us to hear more clearly what was being said.

The letters ranged widely from those which spoke glowingly of psychiatrists who had helped them considerably to those who found us at best “useful,” at worst, abusively powerful, and, more commonly, peripheral to their lives. We were distressed that they found some of us unhelpful and apparently lacking in empathy and responsiveness to them. At the same time, we were inspired by the opportunity to communicate what we were hearing—now that we were listening in a different way.

Our purpose is to tell the reader what we heard about the lives of the people with mental illness who wrote to us—about how they felt in general about its onset and its effect on them, and about what helped in their rehabilitation and recovery. In addition and in particular, we heard how patients felt about their psychiatrists and their treatment

relationships. We hope the reader—whether a person with mental illness, a family member, or a clinician—will also listen and find the report useful.

ONSET OF THE ILLNESS

Dear Abby,

One morning I woke up and the shit hit the fan. I was paranoid, suicidal, and felt I was worthless. I was so paranoid that I just knew that the whole world was against me. Suddenly, I wanted to go to the hospital for help.

About this time my hallucinations began as voices. I remember walking to my room and hearing voices coming out of my closet. The voices of old friends and my sister telling me that I was worthless and trash. These voices scared me. That was the first time I heard voices. They were telling me that I was right about the way I felt about my life and that I deserved to die. The voices blew me away with what they said to me, and to this day, still do.

Here is a vivid description of the experience of a first psychotic episode and the fear that is usually associated with it. This is a crucial time for patients, who may be affected by the treatment they receive for years to come. Finding the right psychiatrist at this time can make an enormous difference.

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FINDING THE RIGHT PSYCHIATRIST

Making contact with a helpful psychiatrist from the start can be very valuable for people feeling overwhelmed by mysterious, frightening, and powerful forces beyond their control. This can be the opportunity to receive clear, straightforward, and compassionate communication. The psychiatrist, in as sensitive and clear a way as possible, can talk to patients about the nature of a psychotic episode and its treatment. The patient may not be able to fully comprehend or accept the information offered, but may nonetheless feel reassured that the psychiatrist has a grasp of the problem, is caring and ready to help, and is willing to discuss what is happening and what should be done.

Some of the letters reported such experiences:

Dear Abby,

I had a breakdown over twenty years ago. I had some problems with this sickness before that, not knowing at the time what I had. I've had the same doctor over twenty years. He was the very first psychiatrist I saw, God bless him, and is a very caring man. I now see him once every one to two months. Years ago he tried at times to take me off the medication but by the third or fourth day I started to get sick again. He helped me to learn that I need to be on it for the rest of my life. His advice to watch my stress level has also been very important.

I hooked up with a doctor who prescribed my medicines. She became my therapist altogether, for talk and medication. She is my lifeline, with a very, very, long rope. Our work together has saved my life and turned it around altogether.

Other letter-writers were not so lucky:

After my first breakdown I saw a Dr. X for four years. He cared little about me. He told me all about his family and patients and even answered his messages during my appointment. I am ashamed to say it took me three years to realize what a jerk he was, and another year to not listen to his persuasion that I really did “need him.” I finally just walked out of his office and never went back. He still prescribed my medications, even though I had gone to an LCSW for therapy. He did that for a year or so, without ever seeing me.

My first psychiatrist was an absolute turd. He would not communicate with me at all and when I left the hospital I still did not know what was wrong with me. Oh, my family may have been told, but I was not, and who had more right and need for information than me, the patient, the one whose life was the most affected by this disorder. I was no longer a child, but a full-grown

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adult when I had my first illness, but I was treated like a child. I was treated also as if my IQ level had dropped below the status of an imbecile.

I do wish that my doctors had taken the time to explain my illness to me. I wish that someone could have given me advice on how to handle the mental illness that I was experiencing, for I had never experienced anything like it before.

THE EXPERIENCE OF PERSISTENT ILLNESS

When acute episodes evolve into persistent mental illness, powerful feelings accompany the process. These include grief, fear, and desperation, and a sense of powerlessness and loss of control in the face of this radical disruption of life's course. There may be pain and sadness about lost opportunities and altered relationships to loved ones. Other reactions include denial of the problem, anger at the unfairness of fate, and unhappiness with treatment experiences, especially those that involve coercion.

Dear Abby,

For the first three years that I was in treatment, I did not believe that I was ill and tried not taking my medication. I felt oppressed by the judgment of my doctor and I planned to leave my treatment and move to California. When my doctor learned I bought a plane ticket to Los Angeles, he had me committed to a hospital against my

will. My stay in the hospital gave me a new experience in fear that I had never known before. I felt imprisoned against my will.

Hearing voices is a mixed bag. Voices have been helpful to me in the past, but I also hear contradictory and violent ones. This causes me deep despair.

There is nothing on earth more frightening than the feeling that one is not in control of one's own thoughts and actions.

These feelings were compounded for many by the sense of isolation mental disorder can cause. Some letter-writers reported that friends and family would avoid them and exclude them from parties and functions because it seemed they only wanted limited contact with a “mentally ill person.” Stigma was especially painful because the letter writers could find neither adequate reasons for it, nor the means to combat it.

The letters indicated that the ongoing course of “being ill” was characterized by a struggle for acceptance—acceptance of the reality of the condition and the need for treatment and acceptance of oneself as a worthwhile person in spite of the illness.

Slowly I accepted my illness but wanted to live a full life in spite of it. I was desperate to

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succeed in the real world and I entered college. There I expanded my social ties so I wouldn't have to be forced into the identity of schizophrenia. My teachers give me courage and respect; they know I am schizophrenic and they care how well I do, both in school and in my social life.... All in all, knowing I am mentally ill and need to take medication does not seem so bad any more.

Accepting the reality of being mentally ill is especially difficult for young people just beginning their search for identity and purpose. At this stage, the availability of helpful, caring providers can have a profound impact on a person's ability to make progress. The letters spoke of the role of psychiatrists in this process.

For some, the psychiatrist's prescription of medicine was sufficient.

I was in the hospital for three months. Each day I took three red pills and two blue pills. They cleared up the psychosis like a miracle cure. I had never heard before of the great strides medical psychiatry had taken since the introduction of chlorpromazine in 1955. I thought, once a psychotic, always a psychotic. I was amazed that taking some pills could make the world look so different to me. I believe the introduction of antipsychotic medication has spared me from a life of perpetual mental anguish and perpetual confinement.

Recently I heard a song which put down the

medicines which help the mentally ill, saying that all a person needs is God. Well, it bothers me to hear people who have never had this illness putting down the only thing we have that gets us through the day. And yes, I believe in God, but that alone is no substitute for medication which has literally saved my life.

This last letter-writer was able to develop supports outside the treatment arena, and pursue his search for understanding on his own, defining his mental illness as separate from who he is as a person.

For most of the letter-writers, however, there was an enormous longing for therapeutic contact that went beyond medication. Some were able to find it from psychiatrists. Many were not. Their letters indicated that they felt stigmatized by and distanced from the very psychiatrists on whom they depended for help.

Unfortunately, I have found the psychiatric profession sadly lacking in the necessary skills of human empathy to be of much assistance; in fact, I found the treatment dehumanizing and far more detrimental than helpful

The many psychiatrists at the program engaged in the worst sort of mystification. How? I asked, Why and will it happen again?; How can I keep it from happening again?; Should I talk to someone? No information was offered, no guid-

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ance, and questions were not encouraged, and never answered in a meaningful way. The most pompous of the many pompous persons assured me that 'A little knowledge is a dangerous thing.,' as if he were the best authority on me, a stranger to him. Mostly I was told to take my medicine and show up for my next appointment, the implication being that the only things I could do for myself were to take their drugs and follow orders. No attempt was made to treat the outbreak of psychiatric illness as a personal call for growth.

This writer did eventually find a psychiatrist who provided a caring psychotherapeutic relationship that promoted her progress toward recovery.

Numerous letter-writers reinforced this woman's sentiments. As one woman wrote, quite directly:

Be aware that drugs can treat the biochemical imbalance in the brain, but only human contact, talk therapy, friendship, support groups, and the active and willing participation of family in the therapeutic process can heal the mind, the thinking, attitudes, and emotional tendencies.

Most of our patients look to us to go beyond prescribing medication and to make empathic, sustained, therapeutic contact so they can move past symptom control toward a process of personal recovery.

HOPE AND RECOVERY

Dear Abby,

You would do us all a favor if you would publicize the fact that there are a great many of us who, with the help of our psychiatrists, are living normal, productive lives, and are assets to our communities.

In 1978, after the loss of a job, and again in 1980 under similar circumstances, I was committed to a nearby state hospital, the diagnosis: paranoid schizophrenia.... Currently, I see no therapist and take no tranquilizers although I keep an 'insurance' supply of medications which I occasionally take under extreme stress... I have found a peace of mind which transcends the most unsettling life events and see myself as a person of considerable strength and resilience.

The stories we received were poignant and pointed reminders that our clinical training and experience exposes us more to the "illness" in our patients than to their capacity for wellness, strength, and growth. These letter writers were not just "patients," but whole people, whose dignity, courage, pride, and spirit shone through in spite of all the suffering associated with their illnesses.

Many writers described a hopeful outcome and a process of recovery. Many had overcome the terrible adversity of being ill; they persisted, continued to struggle, and found hope.

RECOMMENDATIONS FOR CONSUMERS AND
FAMILY MEMBERS

The letters, taken together, identify some of the most important steps or components of this recovery.

Step 1. Maintain Hope

For many years, I have struggled with different types of mental illness: paranoia, severe depression and schizophrenia. I'll never be fully cured, but that doesn't mean I can't live. I now attend support groups once a week and still (for the rest of my life) take medication. I have been working for over seven years, and things are looking up. I want to be a role model. To all the people who think they can't survive that illness, just remember me.

The process described in the letters is by no means smooth. Hope is not easy to find when one is afflicted with a disabling, stigmatizing, mental illness.

I hear words like psychosis. It just doesn't leave much for a person to look forward to.

I'm so frustrated. I have so much to give, and I can't because our society is so afraid of what they think...I don't want to just exist. I want so much to make a contribution—to make a dif-

ference.

Step 2. Measure Success in Small Steps

People begin to develop tiny sparks of hope in the midst of enormous pain, often through small steps forward.

No symptoms are present—it has been something like a miracle. I am told that if I continue my medication I will probably be able to have an apartment and a small part-time job.

Success is getting out of bed in the morning. It's brushing your teeth without staff prompting. Success comes from remembering what time to take your meds, leaving the facility once a day. There is success in everything you do throughout the day.

Step 3. Seek Support

For many, support was an essential ingredient in recovering. In many instances, psychiatric support combined with peer support and religious faith to promote healing.

I have the support I need to take charge of my illness. I am trying to 'let go and let God'. I give thanks every day for the fresh start dawning,

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for the support of my psychiatry staff and many friends, for the warmth and light reaching my darkest confusion.

I was treated for schizophrenia....I owe my complete recovery to God, a wonderful husband, and a gifted, great psychiatrist.

Some letters specifically emphasize support from family and friends as important complements to treatment:

I am blessed with a caring family. To me, my family's care and insistence that I take my medication is the key to the management of schizophrenia.

Support from other patients and programs can also be helpful.

I also belong to a clubhouse program, and that place is my home. The staff give me love and friendship.

I learned things about life from other patients, sometimes just by being in the waiting room.

Other letters emphasized the importance of faith in God, or some form of spiritual strength.

Although I do feel that psychiatric support is very important to a schizophrenic, I also feel very

strongly that in large part my mental health has been very dependent on my strong life of faith. As much as I thank my doctor for his part in keeping me well, I do believe that the greatest thanks belongs to God, in whom I abandon everything.

For some, God and religion are integrated into the treatment.

My recovery has been brought about because of many prayers for me and my family. Both my doctor and I are Christians, and he has been not only a counselor but a friend. God has seen fit to heal me and I give Him all the praise and all the glory.

Step 4. Value Self-reliance and the Determination to Succeed

Ideally, positive support from others combines with and promotes self-reliance and empowerment, key elements of the recovery process:

I'm getting better not only because my new medication works, but also because I am motivated to take it.

Most important of all, Dr. B. encouraged and helped me take control of my life. Recovery is not complete until the person with schizophrenia takes control of their life from a disease that has

robbed them of this gift.

I was experiencing racing thoughts, and at other times I seemed to have so many thoughts in my head that they were crashing into each other. In spite of this, I completed another quarter of college and maintained my 4.0 G.P.A. The real credit goes to my doctor and me. I'm the one who has been through all this and has risen to the top of the water when pushed into a pool. If my doctor believed in me, I took it on trust, and believed in my 'self.'

However, recovery often can proceed even when such support is not available, and in fact, even in the absence of good psychiatric treatment. Sometimes a lack of satisfaction with treatment and support led respondents to place greater faith in their own resources to promote recovery.

Some (psychiatrists) have been good to me, others not....Always I have been a difficult person to help: my current philosophizing and literary ambitions to heal myself has made it very difficult for them to understand me. But through attentive listening, and my own ability at self-help, I grow my way out of much of my illness.

My philosophy at the time was that no one had any reason to care about me and that no one owed me anything, so I must survive on my own

as best as I could do honestly.

I still deal with my symptoms on a daily basis, but I no longer deal with psychiatrists. I have nothing against the profession, they do have their uses, I believe the majority are well-intentioned. In reality, though, I believe they have not advanced much beyond the demon-beating and ice-pick lobotomies of the middle ages....I don't believe there is a cure for mental illness, I do believe that people can learn to make life style adjustments to compensate for a mental disability, much as people with physical disability compensate. At this time, I have no need of a psychiatrist. I pay close attention to my mental state. I keep the stress level in my life to a minimum.

The doctor is never happy unless telling you what to think. Sorry, but I've concluded I'm still a live human in spite of you.

Experiencing psychiatry as unhelpful, some respondents turned to the Bible, or to other sources of spiritual help.

Heaven help the poor person who needs help. They are the test tubes of quackery. It took

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me a long time to realize that I could do a lot more for myself, by turning to the Bible.

In the early years, I was consistently over-medicated and too doped up even to complain. I failed at everything I tried....At age 24, I went off my medication and spent several years off. I began painting, and that and my adopted philosophy of Zen saved my life because here was something I could do.

I live because I want to live, because God wants me to live. It is sad that mental health professionals cannot recognize Christianity as an asset to recovery.

Step 5. Value Productive Activity

Recovery brings with it a desire to find productive activities: to establish a home and raise children, to work, to volunteer, and pursue creative and leisure interests. Many express particular satisfaction about their ability to resume their lives and accomplish new things. There are diverse avenues for this type of satisfaction even when disability persists.

I do work. I am in my second year of college, I function in society and get along with all different types of people.

I am back in college learning to be a floral designer.

I have lived a very productive life in spite of being schizophrenic. I am a retired nurse who brought up three children.

Sometimes recovery is a chance to go back to complete a goal that had to be put aside at the time the illness began.

When I was 52 years of age, I graduated from an Associate Degree program for my R.N., which had been interrupted when I was 21 and had the first episode.

Creative activities are also mentioned.

In a burst of creativity, I wrote three short stories.

I write to over 80 pen pals.

I have written about 30 to 40 poems, and

composed a couple of pieces of music.

Step 6. Learn from Experience

Some respondents were able to provide articulate descriptions of their progress, identifying factors that led to increased hope and a sense of control.

Over the ensuing fifteen years I made steady progress understanding and dealing with my past. I came to see the part I played in the process, what attitudes and feelings led me to do what I did and react the way that I did, what I had felt as a child, and ultimately how to take responsibility for my own well-being. I prospered in my career as a computer consultant, was a responsible father, member of the community, churchgoer and vestryman and all the while grew in faith and understanding. It took a lot of patience and counseling to have a different kind of marriage and be a different kind of parent than that I had seen. It required learning a lot of coping strategies and communications skills. And like a glacier relentlessly moving to the sea, I recovered.

I do credit my faith in a loving God and a loving immediate family with my recovery. It's been sixteen years, Abby, I still have 'moments' when some of the 'insanity' returns. There are mysteries in the experience that I know I'll never fully understand. I simply refuse to dwell on them, but find ways to keep busy and prevent myself from being too introspective.

I am fortunate in that I discovered, regardless of whatever chemical imbalances are taking place on a physiological level, I still have power over my own choices in life. At the time, it was a matter, for me, of selecting realities. Sixteen years later, I can perceive truth in more than one reality, and still be in control. My faith is intact as well as my reason.

I know there are certain aspects of this experience I'll never fully understand. I also know that I do work, and I am not drawing my social security nor living with a stigma someone else placed upon me.

These letters tell us that, while psychiatrists can play an important role, many other factors are critical to recovery.

WHAT WE HAVE LEARNED

The letters, taken together, have led us to the following conclusions:

1. Many people with mental illnesses are independent and articulate and need to be heard as people, not simply as patients or “schizophrenics.”
2. Those with mental illnesses have a great deal to tell us about what they do and don't want from psychiatrists and the mental health system.

3. Some people with mental illness are very satisfied with their psychiatrists, but many others feel their psychiatrists are not providing them with what they want or need.

Our letter-writers clearly articulated their recommendations, and some offered angry admonitions, reflecting the hurt accumulated from many unpleasant experiences with the mental health system or specific providers. Most included thoughtful and constructive recommendations.

Dear Abby,

This is my admonition. Make it known to your patients that you really care. As a schizophrenic, we need all the caring we can get.

The doctors, although sympathetic, have not been that helpful in terms of helping us map out a plan, some way to proceed, explaining what they are doing and why, what outcomes we can and cannot expect, what the next steps will be, if any. It would just help if doctors could tell us everything they know, good and bad, educate us, help with a plan of action, not always want to start at square one.

I think the profession should seek the positive in people and reinforce it. All of us have inner strengths on which to draw to enable us to overcome and develop into more socially con-

scious persons. I don't believe in hiding the illnesses beneath the heavy layers of drugs, drugs that prevent rational, deliberate thought processes.

The doctor certainly should encourage positive impulses and direct them into appropriate channels. There are many fields of higher education and surely some classroom work should be appropriate.

Psychiatrists shouldn't so readily believe the conclusions of their peers. They should readily return phone calls and be willing to look things up in the library for the patient. They should always keep their patients confidential from everyone. And if, after a couple of months, they don't feel they can help a patient, they should tell him that so that the patient doesn't waste years of his life and thousands of dollars on useless therapy.

One writer directed her comments to other patients:

Be assertive in seeking a doctor who respects you as a patient and a person and who is generally eager to work with you; you have nothing to lose.

Educate yourself about your condition. Men-

tal illness is one of the few areas where we throw up a wall of silence and denial in this society. Our treatment of the mentally ill, given the resources and information available, is barbaric.

The most healing experience is laughter. Make it your homework every day to find something humorous, something beautiful, something pleasurable in life. Remember, therapy is our sacrament theater, not life. Get back into life.

Even if there is no 'cure' for your condition, there is hope that you may be restored to a high level of function. The proper medication will not 'control you' but rather allow you to control yourself.

And then this writer offers advice to family members:

For those who live with the mentally ill, the most hurtful thing you can do is to take the threatened and defensive stance. You also need to educate yourself about how to react. It is so important not to give up loving and caring about these people. They are sensitive to your hopelessness. A cool, calm, and collected attitude is more helpful than a worried and distraught or over guarded manner, particularly in schizophrenia where the person is at a loss to express affection. He or she still needs to be touched and hugged.

We can summarize the letters' recommendations this way:

- Be caring, humble, and hopeful with us.
- Provide us with education and information.
- Assist us with planning and decision making.
- Promote the positive and encourage growth in us.
- Help us to work through painful feelings.
- And, most important of all, treat us like capable and sensitive human beings, not passive objects.

RECOMMENDATIONS FOR PSYCHIATRISTS AND OTHER MENTAL HEALTH PROFESSIONALS

To provide the care the letters suggest patients are seeking, our profession needs to give further consideration to the following perspectives:

1. Enhance Training

In the era of biological psychiatry, psychiatrists are being increasingly taught that medication treatment for people with schizophrenia is more helpful than psychotherapy. We must continue to emphasize that learning how to talk to patients is just as important as how to medicate them.

2. See the Whole Person

Psychiatrists are taught to diagnose and treat the acute

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manifestations of illness, and to provide maintenance for chronic conditions. This is essential, but unfortunately, the process of recovery and strength-based rehabilitation strategies are less likely to be the focus of treatment.

3. Recognize Stigma

Psychiatrists can have the same prejudice toward people with schizophrenia as anyone else, and for some psychiatrists, an awareness of the severity of psychosis may result in distance and condescension rather than empathy, particularly among those who prefer “healthier” patients.

4. Make the Best Use of Treatment Time

As the “typical” psychiatric intervention has become the brief medication visit, often because of funding constraints, many psychiatrists have come to believe that empathic contact is no longer possible. Clinicians need to recognize that they can make effective contact with patients even during brief visits.

5. Respect Autonomy

Some psychiatrists may feel “safer” in maintaining control to protect the patient from risk and possible relapse. While this may reflect genuine and realistic concern, it can also hinder a patient’s development and recovery.

This list is incomplete. But we hope it provides readers with some understanding of factors that contribute to difficulties that psychiatrists may have. What can be done? In a previous report (A Resident's Guide to the Treatment of People with Chronic Mental Illness)² this Committee endeavored to develop a training curriculum and textbook for both trainees and practicing psychiatrists that emphasized skill development in empathic psychosocial and psychotherapeutic interventions.

In one sense, the letters we received confirmed our observations in that report. In particular, psychiatrists must be encouraged to go beyond psychopharmacology in treating people with schizophrenia and develop caring relationships that communicate empathy, hope, and positive regard, even with the most disturbed patients, and even in the briefest contacts. Simultaneously, psychiatrists must learn more about recovery and rehabilitation as well as about disease, so they can effectively focus on developing an individual's strengths and potential throughout a possible life-long struggle with a disabling condition.

In another sense, however, now that we have "listened" to these letters, we suspect we did not go far enough in our previous report. We need to emphasize more strongly to psychiatrists (and other mental health clinicians) and to teachers and students the absolute necessity of listening to the consumer. Above all, the treatment must be sensitive to the "whole person" being treated, not to the theoretical constructs of our professions. And reimbursement mechanisms need to build in the importance of incorporating these roles.

32 **Now That We Are Listening**_____

We hope that this small report can become a tool for conveying this message. We plan to distribute this report widely to psychiatrists and psychiatric residents—as well as to policy makers and other mental health professionals. We thank those who have written us, and hope other readers who are consumers and family members will listen carefully and pass this report on to those who provide your treatment and care.

Thank you for listening.

FOR FURTHER INFORMATION:

The National Alliance for the Mentally Ill (NAMI):

Telephone: 703-524-7600

Website: www.nami.org

The National Mental Health Association (NMHA)

Telephone: 703-684-7722

Website: www.nmha.org

The National Empowerment Center

Telephone: 800-769-3728

Website: www.power2u.org

The Substance Abuse and Mental Health Services Administration (SAMSHA)

Telephone: 301-443-2792

Website: www.samhsa.gov

The American Psychiatric Association (APA)

Telephone: 202-682-6000

Website: www.psych.org

Address comments about this booklet to:

Committee on Psychiatry and the Community

Group for the Advancement of Psychiatry
PO Box 28218
Dallas, TX 75228 www.psychgap.org

REFERENCES

1. Group for the Advancement of Psychiatry: A Family Affair: Helping Families Cope with Mental Illness—A Guide for the Professions (GAP Report No. 119). New York, Brunner/Mazel, 1986
2. Group for the Advancement of Psychiatry: A Resident's Guide to the Treatment of People with Chronic Mental Illness (GAP Report No. 136). Washington, DC, American Psychiatric Press, Inc. 1993