

Mental health recovery is an ongoing process, not a single outcome. Each person's recovery experience is unique. By making a personalized, inclusive plan for managing a mental health condition, a person has the best chance of living a meaningful life.

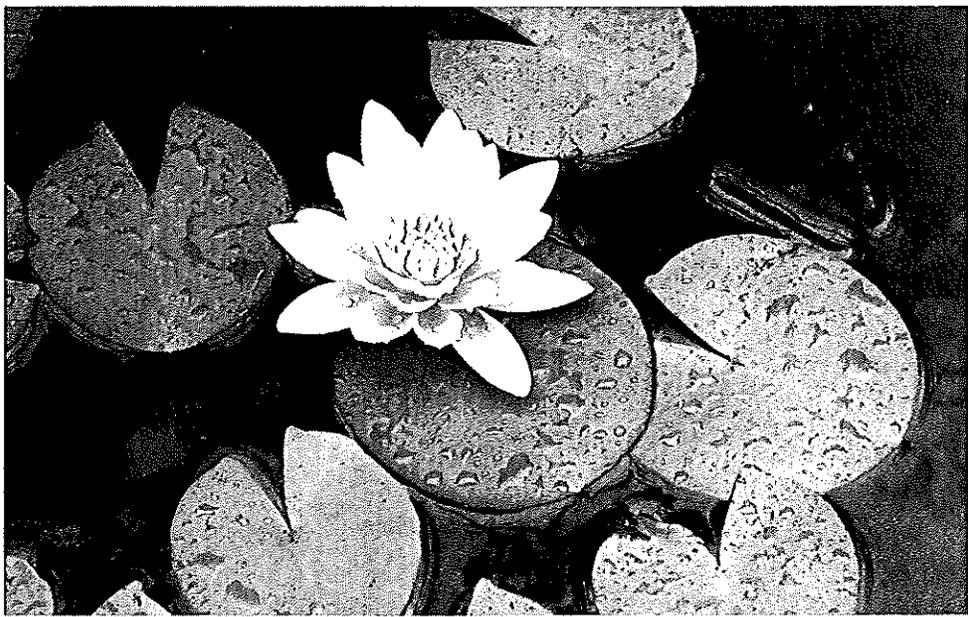
choices in RECOVERY

Support and Information for Schizophrenia, Schizoaffective, and Bipolar Disorder

2012 VOLUME 9 / ISSUE 3

The Wisdom of Experience





Choices in

If this is your first time here, welcome to the Choices in Recovery newsletter. If you have been part of our reader community for a while, welcome back! We're glad you are here.

Our goal is to provide an experience that's warm, friendly, and supportive—because that's what the Choices in Recovery program is all about. We're committed to supporting people with serious mental health conditions and the people who love and care for them.

This issue of the newsletter is full of useful information and interesting recovery profiles. We hope it offers knowledge and insights that benefit each person's unique journey of mental health recovery.

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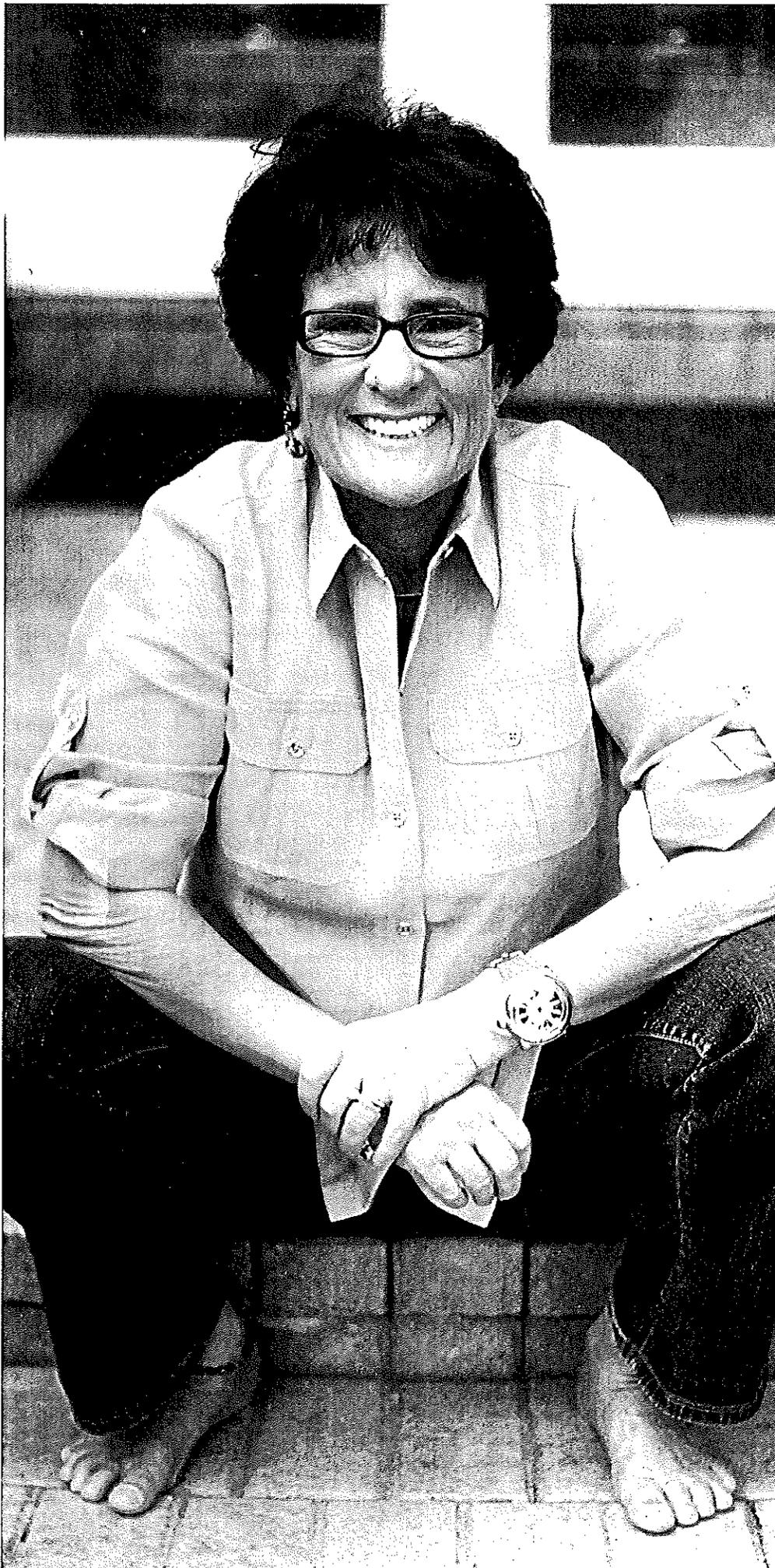


Lori Jo Baach has lived with schizophrenia for 36 years, and today, her life is thriving. She is a wife, a peer specialist, and a published author. In this profile, she shares the experience of her recovery process.



8

Dr. Ronald Diamond offers useful information about coping with a new diagnosis and beginning to create a recovery foundation.



RECOVERY PROFILE

LORI JO BAACH

The Wisdom of Experience

Lori Jo Baach received a diagnosis of schizophrenia 36 years ago. Initially, doctors told her parents there was no hope for her. Lori Jo spent most of her 20s in and out of crisis stabilization units.

Today, her life is a complete turnaround from those early days. Lori Jo has not been in the hospital since the late 1980s. She is a published author. She works for a behavioral health organization in South Florida and she teaches peer-to-peer courses for NAMI. She is married to a man who has learned how to support her when her symptoms become challenging.

Lori Jo credits her recovery to finding a medication that works well for her, having a solid team of people to support her, and talking with a therapist regularly about what's going on in her life.

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The key elements to what helped me—number one was medication, number two was family support, and number three was therapy.

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Q&A

The Early Years: From Diagnosis to Stabilization

CIR: Can you describe what it was like for you in the early years of your condition?

Lori Jo: The onset of my illness was at age 17, and my symptoms really were the worst at age 22. It was horrible. When I first started hearing voices, I didn't know what schizophrenia was, and I thought I was possessed. I was afraid to tell anybody about these voices because I was afraid that the men would come in the white coats and carry me away to an insane asylum where I'd be for the rest of my life.

So I told nobody about these voices at the beginning and kept them contained. But after you keep so much inside, eventually it's like a volcano and it erupts, and I mean it explodes where it's out of control. My first break, I was actually hospitalized at a hospital in New York, and my father knew the doctors there. He didn't want me to be on a psych ward because of the stigma. He thought it was all a mistake. He had connections so he had me admitted to a medical ward instead of a psych ward.

CIR: Your onset of schizophrenia was 36 years ago. Was it hard for your parents to understand and accept your diagnosis?

Lori Jo: [My dad] is very modest. My dad and my brother came to visit me [in the hospital] and I took off all my clothes and started running down the hall and, you know, that was pretty odd. So something was definitely wrong, and then I had another incident and they couldn't figure out what was wrong with me. When the doctors told my parents that I was hallucinating, my parents couldn't grasp the concept. "How could our daughter be hallucinating?" It was just incomprehensible to my parents. They were in such denial and it was a whole process for them to understand.

They would come and visit me in the hospital and sometimes I would be lucid and sometimes I would be out of it, and they blamed themselves. In time, they learned that mental illness is a guiltless illness and that it wasn't their fault.

My dad got his master's degree in clinical psychology and his PhD in industrial psychology and [back then] he was educated that mental illness was a direct result of parental upbringing, and he blamed himself, and my mom blamed herself as well.

Lori Jo's parents saw their daughter suffering—spending the better part of her 20's in and out of crisis stabilization units. Her doctors tried numerous medications, psychotherapy, and electroconvulsive therapy. But nothing seemed to work well; she still felt terrible and lived with debilitating symptoms. Lori Jo recalls feeling like a “zombie” due to the high doses of medication she was taking.

She eventually entered a clinical trial for a new medication that had not yet been approved by the FDA. She and her family felt it was a risky move at the time. They feared the unknown and serious potential side effects, but felt there was no other option.

The risk paid off. Finally, Lori Jo found a medication that worked for her. She says it was the turning point in her recovery. “This medication [which today is FDA approved] worked and it just changed my life and I'm still on that medication today.”



Building a Recovery Foundation

CIR: What has helped you stay on track with your recovery?

Lori Jo: When I first got sick the doctors told my parents, there's no hope, she's a paranoid schizophrenic who will never get better so you might as well put her away. My last hospitalization was in the late 1980's, and I haven't been back in the hospital since that time. That's probably because the [strategies] that I've learned to help me with my recovery and to stay out of the hospital are very strong.

The key elements to what helped me—number one was medication, number two was family support, and number three was therapy.

CIR: What does it mean to you to have a strong recovery team?

Lori Jo: It's important to have people in your life that you can depend on, and that includes family, doctors, people in the community, people that will be there for you that you can count on for different reasons,

whether it's medical, things going on at work, or things going on in your life. Depending on what the issue is, you [need to] have people that will be supportive.

CIR: Can you describe ways that your recovery team helps you in your recovery?

Lori Jo: I've had instances where treatment team members—like my therapist—will see me right away if I need to see them. Even today I'm not voice free. My husband calls my voices “the visitors,” so he'll be on “visitor patrol.” He can tell when I'm hearing voices and he'll say to me, “Come on let's take a walk or something” [to help me relax and get through the symptoms]. There are people in my life who are always watching out for me and able to help me if they need to.

I would do anything to stay out of the hospital and use all my supports to help me do that. If I start seeing myself slip, I call my psychiatrist or call my therapist. You have to help yourself, too. Because bottom line, you're in

control and if you start to feel symptomatic, you need to know to use those supports. I also tell people to always have their medications written down and with them. This is an important thing to do.

CIR: Are there any particular supportive treatments that are important to you?

Lori Jo: I think therapy is important. I see my therapist every 3 weeks and I talk about what's going on in my life—work, financial issues, or weird thoughts I might have. More than anything, it's an outlet for me to share with my therapist about things that I'd rather share with her than with my husband or my friend at work or something. Just to bounce [my thoughts] off her and have someone objective give me feedback and present a different perspective than I would have on my own.



“Don’t give up! There may be a medication out there that can help you. You just have to think positive and be patient.”

Medication and Recovery

CIR: What do you think people who are in the early stages of recovery should know about treatment with medication?

Lori Jo: When you’re put on a medication, you have to stay with it for a while because it [can] take a while to work. So you have to stick it out and really have to give it a chance. Your doctor will tell you how long it will be before you feel the [benefits]. Sometimes [a medication] won’t work [for you] and then you try something else.

As for the side effects—there are [some] bad side effects, but there are different side effect medications that can help. Eventually you’ll find the combination that works best for you. Find a doctor that is very knowledgeable and can [help you find the right] combination of medications. Don’t give up! There may be a medication out there that can help you. You just have to think positive and be patient.

CIR: How important is good communication with your psychiatrist?

Lori Jo: It’s very important. It takes time to really be able to open up and not omit information, but be open and honest. You have to be able to feel that you have a true partnership so you can tell them what you need. Because just like [any person], when they go to a doctor, you have to know what helps or what doesn’t help, what works or what doesn’t work, and when you go to an appointment, you have to

have a relationship with your doctor where you can be able to advocate for yourself and feel comfortable enough to say, “Look, I don’t think this medicine is working,” or “You know, I didn’t take my medicine for a week because it made me feel fat,” or “I don’t want to take this medicine because it makes me drool.” You have to feel comfortable that you can say anything to the psychiatrist and that they’re going to, in turn, help you and listen to you. If you don’t like the psychiatrist for valid reasons, then go find one that you can relate to.

You know yourself the best, and what works and what doesn’t work, and you have to speak up and advocate for yourself.



The Role of Peer Support in Recovery

CIR: Some people do not have family members in their lives to lean on for support. Can you talk about the role of peer support in the recovery process?

Lori Jo: I have people that I spend time with who are peers. I have one friend that I met when I took my peer class before I was a mentor and that was about 4 years ago, and every month I go out to lunch with her and we can talk about anything. It's a special kind of friendship because we can talk about anything and not feel like we're going to be judged. We just feel totally comfortable.

CIR: One of the ways you give back to the community is through your career as a peer specialist. Can you tell us about that?

Lori Jo: A peer specialist is someone who has been on both sides of the fence, they have a mental illness, and they work with people who have mental illness. It's an understanding. Many times they'd rather talk to you than with [treatment team members] with fancy titles because when they say, "You know what's it's like to take 15 pills a day?" I say, "Yeah I do, because I take 31 pills a day."

And if they say, "You don't know what it's like to tell your same story to a psychiatrist because they change psychiatrists every three months," I'm like, "Yeah I do, because I've done the same thing." Or "You don't know what it's like to have dry mouth," and I'm like, "Yeah I do, but I can give a



suggestion on what to do." I can relate and I can validate their feelings and often I can give suggestions that can help.

People feel more comfortable because they can share and know that [their peer specialist] understands. Like how horrible is it to hear voices—you can't imagine unless you've heard them.

I [currently] work for the oldest not-for-profit behavioral health organization in South Florida. I am part of an ACT team [Assertive Community Treatment]. I take people grocery shopping, teach them how to grocery shop. I help people learn how to clean their apartments. It's very hands on. I teach them how to budget their money. I'm also very involved in NAMI and I teach a peer-to-peer program there.

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LORI JO BAACH

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A Fulfilled Life

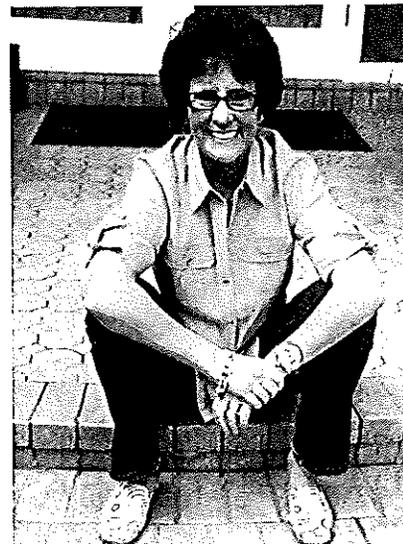
CIR: Are you happy with your life today?

Lori Jo: Very, very much so. I guess it's a journey, but to be where I am today, I am so happy and my life is so fulfilled now. I've been married for over 11 years to the most wonderful man in the world and I look forward to so much. It makes me feel good to give back, which I do every single day in one way or another—so other people benefit from my journey. I'm involved in so many things in this community, sitting on different boards, sitting on different committees. I try to be very motivating and get people excited about something and to think that there is hope. There is hope, and you can't give up.

CIR: Speaking of hope, can you tell us about the book you wrote?

Lori Jo: In 1994 I wrote a book based on the journals that I kept while I was in the hospital and it's called *The Quiet Room: A Journey Out of the Torment of Madness*. It's nonfiction but it reads like fiction and it tells my story from the viewpoint of different people in my life. In 2011, I wrote a short afterword to the book—an encapsulation of the highlights of what transpired between 1994, when the book was published, and 2011. It tells that I got married, that my parents finally sleep well at night, discusses my working experience as a peer specialist, it depicts my battle with drug addiction—which I've overcome—and which is an amazing thing. It also includes discussion questions for book clubs or universities.

I'm proud of it and it's a life-changing book for many people, very inspiring, and again, it's a way to give back and that makes me feel good.



CIR: Are there any words of advice that you would like to share with our readers?

Lori Jo: I would say get as educated as you can. Listen to other people's experiences. And talk. I kept so much inside. Really verbalize what's going on with you, get the resources, get the help, don't be afraid, mental illness is okay. I mean it's not a horrible thing. People have [mental health conditions] just like they have diabetes, or heart conditions, or high blood pressure. It's okay. It's not a horrible thing to have a mental illness. It doesn't mean you're a bad person.

When I sign my books, [I write] "With hope comes miracles." So you can never give up hope because there is always something out there that's going to help, whether it's medication or finding someone [who will] help you.

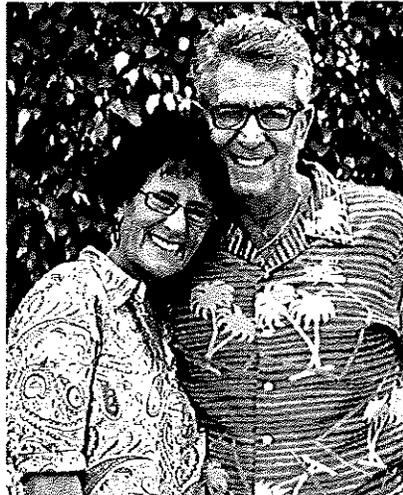
Spouses and Recovery: Finding a Healthy Balance

Steve and Lori Jo Baach have been together for more than 11 years. After all that time, one thing's for sure: their love, respect, and support for each other is strong.

Steve was introduced to Lori Jo by her parents, who invited him to attend a speaking engagement she was giving about her life with schizophrenia. Her parents suggested that Steve read Lori Jo's book before meeting her. After the event, Steve and Lori Jo chatted. Confronting her own internalized stigma, Lori Jo wondered why he would want to go out with someone with her condition. But Steve simply liked her. He asked her to dinner. "The rest," he says, "is history."

When they met, Steve did not know much about mental health but was open to learning. From the beginning of their relationship, he was attuned to Lori Jo's symptoms. "When we first started dating, I could tell when she was, as we called it, 'having visitors.' She would get into a sort of trance." Steve would suggest that they take a walk to help Lori Jo to relax.

Steve has always felt protective of Lori Jo, but does not let the fact that she lives with schizophrenia define their relationship. "Lori Jo has a mental health condition, but she's a human being. She's like any other woman. As the spouse, out of the corner of my eye I'm always looking out after her. [But] you can't be overcautious. You still have to let people live a normal life."



Her personal alarm clock, a helping hand

Steve has learned that mental health recovery is an ongoing process. He has a deep appreciation for what Lori Jo has gone through to achieve the quality of life she has now, and he helps however he can. He talks about the sheer number of pills his wife takes each and every day to manage her mental health condition and says Lori Jo is receptive to having him do what he can to help her stay on course.

Lori Jo is receptive to having Steve remind her to take her medication. He also makes sure she's up in time for work in the morning because her medication causes her to sleep deeply. But Steve feels he does it in a matter-of-fact way. "As the spouse, you realize these medicines are

necessary. You have to be supportive and say, 'Did you take your medicines in the morning? At night?' You've just got to be there and say, 'Hey, this is what you need.'"

Supporting Lori Jo's career, decreasing stress

Steve believes Lori Jo's involvement in her career is important. He proudly acknowledges that she is a role model to others, and that her work is rewarding to her. "She tells her story, she lets people know that she has a mental illness, but she's trekked on through it and she works in the mental health field," he says. He has found that stress can exacerbate Lori Jo's symptoms. One way he helps reduce the stress levels at home is by helping with the housework. To manage his own stress, Steve walks 3.5 miles each morning.

Time together creates a healthy, loving routine

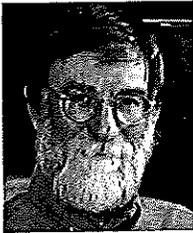
Spending as much time together and being affectionate and communicative when they are at home is important to Steve. "We're always together. We sit together after dinner, we watch TV together, it's our routine."

The best advice Steve has for spouses and partners: "First, make sure you love the person. Next, always be there when they need you. Be as supportive as you can be. And let things work naturally; don't force issues."

These words are a good foundation for any loving relationship, whether or not a mental health condition plays a role or not.

RECOVERY

Insights



WITH DR. RON DIAMOND

Psychiatrist, and Choices In Recovery Editorial Board Member

This information should not be considered a consultation regarding a person's medical condition.

Readers are advised to rely on their own doctor for information regarding diagnosis and treatment.

When you tell people that they have a serious mental health condition, how do they begin to cope?

People have a variety of initial reactions when first given a diagnosis of some terrible illness, be it cancer or schizophrenia. The initial reaction is often "Not me, this can't be the correct diagnosis for me." There is often denial and pushing back against the caregivers trying to help. Many people are not ready to enter into a calm, thoughtful, rational discussion.

Sometimes a person is relieved that there is now a name to the problem, that someone else knows about it and there is help.

Whatever the initial reaction, it may take some time for the person to go from the initial reaction to the point where they are ready and able to listen.

Many people are already confused, frightened, and trying to make sense of what is happening.

Fighting the diagnosis is just a part of the desire that it should all just go away and things should be normal again. But this is not always the initial reaction.

It is always important for the clinician to listen to a person's understanding of what has just been said. There are always and inevitably distortions when someone is initially given a serious diagnosis. The person may hear it as something minor that will go away, or something so overwhelming that no hope is possible. The confusion from the mental health condition can just add to this very human process.





What do you feel is the first step of the recovery process?

Reestablishing a sense of hope is often the most important step in recovery. Medication can be administered that often helps provide some basic stability, but finding hope that life can reestablish itself is the beginning of the recovery dialogue. Just asking about personal goals and dreams is a way of helping the person think about a future that may have more to it than just illness.

Once there is hope and a goal, then there must be support for the very hard work of rehabilitation. Things that once were easy may be more difficult. As with any rehabilitation, recovery takes time and motivation. Sticking with a program that may, at times, feel frustrating and overwhelming, can be difficult to do on your own.

What are 3 practical steps people can take when beginning to create their recovery foundation?

1. Develop personal goals. These can include short-term goals (things you would like to work on and change in the next few weeks or months) and long-term goals (a journey that may take years). Write these down, and try to make them as specific and concrete as possible. They may change over time, so writing them down does not mean they are locked in concrete. Writing them down does help to make them real.

2. Develop an action plan. How are you going to start working towards these goals? What is the first step, no matter how small? How would you know if you were making progress? Whose help do you need, and what kind?

3. Start! Stop just planning and begin organizing!

Begin to do something that will get you one step closer to where you want to be. Involve your friends and family and clinicians. At times you are going to get frustrated and angry and feel like giving up. This is not just connected to your mental health condition, it is connected to how hard it can be to reclaim your life. You will need your friends and supports to get you through these times. You need to let them know that they may need to help you maintain hope even if you temporarily don't feel hopeful.



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Editorial Review:

The Choices in Recovery newsletter
receives editorial input and review
from Dr. Ronald Diamond, professor of
Psychiatry at the University of Wisconsin
and Medical Director for the Journey
Mental Health Center. Dr. Diamond has
been actively involved in the community-
based treatment of people with serious
and persistent mental health conditions
for more than 30 years.

In addition, the Choices in Recovery
newsletter receives editorial input and
review by the Janssen Mental Health
Community Advisory Council (CAC), a
group comprised of people living with
serious mental health conditions, family
members, and advocates.

Dr. Diamond and the CAC are compensated
for editorial support provided to the
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and Bipolar Disorder*

Get Information and Support on Timely Topics, Including:

- ▶ Treatment and Recovery
- ▶ Mental Health Conditions
- ▶ Strategies for Success
- ▶ How to Get Involved
- ▶ Caregiver Issues



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