

EDITORIAL

SCIENTIFIC KNOWLEDGE & LIVED EXPERIENCE



entirely in textbooks or laboratories: the knowledge of lived experience.

A person who has experienced depression knows what it means to get through a morning when even getting out of bed feels overwhelming. A young person who has battled anxiety knows the exhaustion of constantly fighting thoughts that others cannot see. A person who has recovered from addiction, survived trauma, or lived with a psychosocial disability understands the mental-health system from the other side of the consultation room. A suicide survivor knows how close he was to dying and what helped him live.

These experiences are not merely stories. **They are knowledge.**

WHO rightly emphasizes that people with lived experience have first-hand insight into the disorder, and its aspects. They have a different set of knowledge that professionals may not have in spite of training and research. Their insights can help make mental-health policies and services more relevant, compassionate and person-centred.

There is also enormous power in sharing experiences publicly. One honest voice can tell another person: **"You are not alone."** It can transform shame into recognition, isolation into connection and silence into a willingness to seek help. When people hear someone speak openly about panic attacks, depression, grief, suicidal thoughts or recovery, mental illness becomes less of an abstract concept and more of a human experience that can be understood and discussed.

This is particularly important in societies where stigma continues to prevent people from seeking help. **Stories can challenge stereotypes more effectively** than statistics. They remind us that mental-health difficulties do not

define a person's identity, intelligence, capability or worth.

But there is an important distinction between **hearing stories and giving people a voice in decision-making.** Lived experience should not become a token testimony invited merely to make a programme appear inclusive. WHO calls for meaningful engagement—where people with lived experience participate in designing, implementing and evaluating mental-health services and policies. The principle is beautifully captured in the phrase: **"Nothing about us without us."**

At *Mind Matters*, we thought we could capture the stories of patients, survivors, and ordinary citizens whose lives have been touched by mental-health challenges. Believe me, it was with difficulty we found only few willing to share while many denied being overwhelmed by it.

We need to listen without judgement, share without sensationalising, and learn without assuming that one person's experience represents everyone's. **Every lived experience is individual; every voice deserves dignity.**

The future of mental health will not be built by professionals alone. It will be built through a partnership between **science and experience, evidence and empathy, expertise and humanity.**

Let us therefore listen to the real voices.

Because when experience speaks, **mental health must listen—and when mental health listens, real change becomes possible.**

Rita Aggarwal
-Editor.

MENTAL HEALTH IS THE BEST WEALTH: SESSION ON BEING MENTALLY FIT & STRONG

Ahead of World Mental Health Day, a mental awareness.

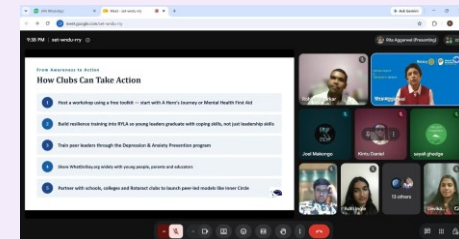
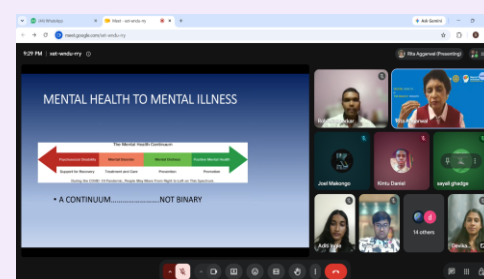
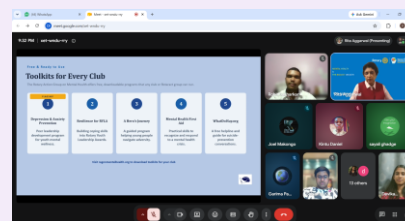
health awareness session titled "Mental Health is the Best Wealth- How to Stay Mentally Fit and Strong" was conducted on 8th October, 2026 by Rotaract Club of Nagpur, in collaboration with Rotaract Club of Njeru, Uganda.

The speaker for the session was Rtn. Rita Aggarwal, Consultant Psychologist and Chair of Rotary Action Group on Mental Health Initiatives (RAGMHI), who shared valuable insights on maintaining mental well-being, building mental strength, and recognising the importance of mental health as an essential part of overall wellness. An interesting part she covered in her session was also about how Rotaract Clubs can contribute and work towards mental health

The interactive session brought together participants from RAC Nagpur, RAC IGGMC, RAC KDK and other Rotaract Clubs from Uganda, creating an opportunity to learn, reflect and engage in meaningful conversations around mental health.

The programme reinforced a simple yet powerful message: investing in our mental health is one of the most important investments we can make in ourselves!

-Devika Gokhale
Counselling
Psychologist,
Nagpur



SCHIZOPHRENIA: A STORY OF STRUGGLE, RECOVERY & HOPE

I am sharing my story because I want people to understand something very important: **mental illness can happen to anyone**. It does not matter where you come from, what your background is, how educated you are, what your religion is, or what kind of family you have. And having a serious mental illness does not mean that your life is over.

I have lived with schizophrenia and other mental-health challenges for many years. I am still overcoming some of my disabilities, but when I look back at where I was in my twenties and where I am today, I realize how far I have come. It has been a long and difficult journey, but I made it—and I am still moving forward.

I was born in 1980 to wonderful parents, Joe and Patsy Schramm. I had a loving childhood and a good upbringing. I did well in school, enjoyed sports and was particularly passionate about tennis. I was active, played on teams and dreamed of becoming a physical therapist. I also volunteered in hospitals and therapy departments because I loved helping people.

During my teenage years, however, things began to change. I started drinking heavily, smoking and spending time with the wrong crowd. My school performance suffered. Looking back, I believe that alcohol may have been masking depression and other difficulties that I did not understand at the time.

After high school, I went to college, but I struggled. At the same time, my family moved to another area. I had been deeply attached to my childhood home and found the move much more stressful than I could explain to my parents. I kept my feelings to myself because I did not want to be a burden.

Eventually, everything seemed to come together in what I now think of as a “perfect storm”—the move, relationship difficulties, college pressures, worries about my future, and other stresses. Around that time, I also began taking medication for acne. I personally believe this may have triggered or accelerated what was already developing in me, although I know that we can never know for certain.

Then my mind seemed to break.

I began experiencing psychosis. My thoughts raced uncontrollably. I became confused and frightened. I walked the streets, prayed and behaved in ways that made no sense to other people. Police and hospitals became part of my life. I experienced repeated episodes, depression and profound emotional distress.

It took several years and many doctors, psychiatrists, counsellors, tests and medication trials before I finally received a diagnosis. Eventually, I was diagnosed with schizophrenia with psychotic features and hyper-religiosity. Having a name for what was happening to me was important. I began to understand that **I was not the illness; I was a person living with an illness**.

One of the darkest moments of my life came during a severe psychotic episode when I heard voices telling me that I was worthless and should end my life. I did not really want to die. I wanted the unbearable pain and confusion to stop. I attempted suicide, but I survived.

My parents found me and got me to the hospital. I cannot fully describe what that period was like for me—or what it must have been like for my parents. They watched their daughter struggle with an illness they did not understand and had to confront the possibility of losing me.

That experience taught me something I will never forget: **mental illness affects the whole family, not just the person who receives the diagnosis**.

My parents never stopped encouraging me. They learned about mental illness, sought support and continued to stand beside me. I also discovered the importance of community. I lived in a group home where I learned practical skills, medication management, coping strategies and how to take greater responsibility for myself.

Faith has also been central to my recovery. My relationship with Jesus Christ has given me strength, meaning and hope. My faith does not replace

medical treatment, professional care or medication, but it has been an important source of comfort and resilience for me.

Eventually, I found a psychiatrist I could trust. After years of trying different medications, I found a treatment that helped bring stability and reality back into my life. Accepting that I had schizophrenia took many years. For a long time, I was angry and asked why this had happened to me. Gradually, I learned to accept my condition and to focus on the life I could build rather than the life I thought I had lost.

And what a life it has become.

In 2006, I began working as a caregiver with Home Instead Senior Care. I was frightened about returning to work, but I took the opportunity. I stayed for twenty years and cared for many older people. I formed meaningful relationships and learned so much from the people I served.

I also discovered my love of running. I started with just a few minutes at a time. Eventually, I completed 5K and 10K races and later five half-marathons.

I returned to tennis too—the sport I had loved as a young girl. I had to overcome my own feelings that I did not belong, particularly because many people at the club were wealthier than I was. But I kept going. I practiced, joined teams and tournaments, made friends and rediscovered something that had always been part of me.

I also went back to college despite being told that I might never finish. In 2010, I graduated from Southeastern Louisiana University with a degree in Business Administration. My family came to watch me walk across the stage.

My journey eventually brought me to Rotary. I was invited to speak at the Rotary Club of Mandeville, received a standing ovation and became a member. Today, I participate in Rotary projects and serve as chair of the club’s mental-health committee.

Service has become an important part of my recovery. I have participated in mission trips to Brazil and worked with children. I am also involved with the Exchange Club of West St. Tammany and fundraising for Hope House, which supports children affected by abuse and provides counselling, anger-management, self-esteem and mentoring programmes.

Looking back, I know that recovery is not a straight line. There have been setbacks, loneliness, stigma, medication challenges and days when I did not believe I could continue. But I have learned that **a diagnosis does not define a person’s worth or potential**.

Today, I have meaningful relationships, work, service, sport, faith and a community around me. I am grateful for every birthday and every opportunity to help another person.

My message to families is simple: **please do not wait to seek help if you believe someone you love is struggling. Early intervention matters**. Mental illness can be frightening, but there is help, treatment and hope.

My message to people living with mental illness is equally important: **please do not give up on yourself**. You may have to travel a different road from the one you imagined, but there can still be purpose, achievement, friendship, service and joy.

I am living proof that a person can experience a severe mental illness and still achieve meaningful things.

I want to use my story to help even one person feel less alone.

If my experience can encourage a family to seek help sooner, help someone with schizophrenia believe in their own possibilities, or help society replace fear and stigma with compassion, then everything I have been through can have a purpose.

I am not finished yet.

I am still learning, still growing, still serving—and still grateful to be here.

Jeanne Schramm



FROM CONFINEMENT TO A LIFE OF DIGNITY



Sunayana was a bright and intelligent young woman from a well-to-do family in a village in Sirsa district, Haryana. The younger of two daughters, she had completed her graduation and had been married into a family of similar social standing. She had a son and was living a happy family life.

At the age of 20, however, she developed symptoms of mental illness and was later diagnosed with schizophrenia. Her family initially sought treatment and she recovered. Unfortunately, the illness relapsed after her marriage, this time much more severely. She stopped caring for herself, her home and even her two-year-old son. She was sent back to her parents, where her condition continued to deteriorate.

The family tried everything they could think of—treatment from several psychiatrists, faith healers and religious rituals. They spent considerable money and endured years of emotional distress, but nothing seemed to help. Eventually, fearing that she might run away and bring shame to the family, they confined her in a small room within their home. For nearly eight years, her world became an 8-by-10-foot room, with food and water passed through a small opening in the wall.

In 2015, a student at a local college told the Nishkam team about a young woman from his extended family who had been living in a locked room for years. The team tried to contact the family, but they initially refused treatment. A few weeks later, while Nishkam volunteers were conducting mental-health awareness work in nearby villages, a school principal mentioned the same young woman and offered to help persuade her family.

When the Nishkam team and doctor visited, her parents were understandably distrustful. They had already tried numerous treatments and had been disappointed repeatedly, at times even cheated. The team assured them that treatment would be provided free of cost and persuaded them to give medical treatment another fair trial.

The change began surprisingly fast. Within a month, the family could see a clear improvement. Gradually, Sunayana began interacting with them, looking after her personal hygiene and becoming calmer and more independent. The family's trust in the Nishkam team also grew. After about three months of treatment, she was released from confinement.

But liberation was only the beginning. With continued treatment and family support, and regular monitoring by the Nishkam team, Sunayana gradually resumed her life. Her transformation became visible in the most ordinary things. The home that had once reflected years of distress became clean and organised. She began preparing meals herself and taking responsibility for household activities. On one occasion, when a Nishkam team member informed the family that he would need a meal while passing through the village, Sunayana herself prepared an elaborate meal for him.

Today, her son is a young man studying in a boarding college. Sunayana herself is increasingly independent and able to contribute to her family and community.

Her journey from confinement to independence reminds us that **mental illness need not mean the end of a person's life, relationships or aspirations**. With appropriate treatment, persistence, family support and compassion, even a life that appears to have reached its darkest point can begin again.

-Contributed by Dr Dhanesh Gupta on behalf of Nishkam Mukti Team.

Note- (Name of the patient and village have been changed)

INTERVIEW WITH SANJAY SINGH - A CANCER SURVIVOR

Nivedita: What was the nature of your illness and the psychological challenges?

Sanjay: I suffered from fourth stage advanced cancer. My immunity dropped. I was attacked by pneumonia, Bell's palsy (which is almost a paralytic attack on the left side of my face). I also had tuberculosis. I was like a moving bomb with these four things on. I underwent 32 radiation and 20 chemo cycles. My weight was reduced from 106 to 42 kilos. I started imagining and talking about death. Everything around me started looking meaningless and worthless. And that created a huge psychological toll on my mind. And this is the time my training in Vipassana meditation helped me.

I went into deep meditation. The more I used to suffer physically, the more I used to resort to meditation and chanting of Vedas which is a great exercise in deep breathing. A huge support from my family made me feel worthwhile. Patience and fortitude, and belief in myself also played an important role. If you don't lose your mind, you have every reason and opportunity to bounce back. But once you allow your mind to break up, you're gone. I strongly believed that I will not allow my mind to drop and that helped me recover.

N: Any other impact of it on your life?

S: Yes, I started appreciating a lot of things in my life which earlier I would not. I started valuing people. The second impact of it was in terms of the process that I normally adopt for doing a lot of my things. Prior to the illness, my process revolved all around me, myself and everything around me. Now, I have become more collaborative. I realised that material wealth is not that important.

There was a time when I thought that I'll give up on work and I will retire. But now I have resumed work and **I have started giving back to society. I have taken an oath of training 1 million people with the science of selling before 2032.**

All in all, in hindsight, **my ailment was a blessing because it taught me so many things, and it has definitely made me a better human being.**

-Ar. Nivedita Singh



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FROM ILLNESS TO ACHIEVEMENT

My journey with **bipolar affective disorder** began during the second year of MBBS. I was a medical student with dreams of becoming a doctor, but suddenly I began experiencing intense examination anxiety and depression. I sought treatment, but during the course of treatment my illness changed dramatically and I developed **hypomania**. I became unusually aggressive and at times violent, even towards my teachers. My behaviour became so difficult that I was almost on the verge of being expelled from medical college.

At that stage, I had very little understanding of what was happening to me. I eventually realised that these were not simply problems of attitude or character, but manifestations of a psychiatric illness. Although I considered seeking help within my medical college, stigma and embarrassment made it difficult for me to do so. I eventually approached Dr. Roop Sidana, and that decision became an important turning point in my life.

Over the past two decades, I have remained under regular psychiatric care. My illness has been severe at times. I required hospitalisation on two occasions, and during one particularly severe manic episode with psychotic features, I required a course of ECT (Electroconvulsive Therapy). At that time, I was extremely unwell and uncooperative; during my hospital stay, I even became aggressive towards a member of the staff. Looking back, these experiences remind me how serious mental illness can become when symptoms are severe—and also how important appropriate, timely treatment can be.

After completing my MBBS, I aspired to pursue postgraduate training. During this period, sleep deprivation and stopping medicines were followed by another manic episode. Once again, I returned to treatment and gradually recovered. Over time, I learnt that managing bipolar disorder is not only about taking medication during an episode; it also involves regular medication and follow-up, protecting sleep, recognising early warning signs and taking responsibility for one's own mental health.

Marriage brought another important challenge. Before getting married, there were understandably concerns about my history of psychiatric illness. I chose to be open with my prospective life partner. With counselling and guidance from my treating team, we were able to understand the illness and its treatment. I married a doctor, and we have built a happy family life together. I have continued medicines and remain particularly attentive to changes in sleep, routine and other factors that may increase my vulnerability.

Today, I am working as a District Medical Officer in Punjab. I am able to perform my professional responsibilities, care for my family and live with dignity.

My message to anyone living with a severe mental illness is simple: do not allow stigma to define your future. **Bipolar disorder can be serious, but it does not have to end your education, career, relationships or dreams.** With appropriate treatment, regular follow-up, self-awareness, family support and compassion, recovery is possible. **You can live with dignity, grow as a person, build a fulfilling family life and contribute meaningfully to society—even while living with a severe mental illness.**

-Anonymous



A WOMAN WHO REBUILT HERSELF !!!

If someone had looked at my life from outside, they would have probably said, *"What more can she ask for?"*

I was a postgraduate doctor and married a doctor. We had similar education, social standing, and family backgrounds. It looked like a perfect match. But some houses look beautiful from outside. You have to live inside them to know how they feel.

After marriage, I soon realised there were many rules, rituals, and religious practices which were wrapped up as *discipline* and *family values*. It took me a long time to understand that I was being emotionally controlled. Sometimes abuse does not come with a raised hand. Sometimes it comes disguised as **tradition, obedience and "this is how a good daughter-in-law should behave."**

Having many children and running a house without help is said to be a good daughter-in-law. Women like me are very good at functioning while falling apart inside. I kept being a mother, wife, and doctor. But inside, I was slowly disappearing. My body became tired first. Then my mind. Then my confidence.

There were days when I could not go to my clinic, even getting ready felt like a burden. My professional life, which I had worked so hard to build, slowly slipped through my fingers. With every missed clinic, every unfinished task, and every criticism, I felt a little more worthless.

I began asking myself, *"What is wrong with me?"* That question haunted me.

I stopped looking after myself. I had become vulnerable and emotionally hungry for kindness. I was exhausted, confused, angry, ashamed and helpless.

At one point, I no longer recognised the woman looking back at me in the mirror. **I had become a stranger to myself.**

And then, somewhere in that darkness, I found Sripriya Ma'am through a friend. I was hesitant, doubtful, and feared the stigma and exposure. Somehow I went for counseling sessions. That itself was a big step.

She helped me understand **myself**. I began to look at myself with the same compassion I had always shown others. Something changed. Not my family nor my circumstances.

I changed.

I began to understand emotional manipulation and to recognise my own triggers. I learnt boundaries and saying *no* did not make me a bad woman. Being a good daughter-in-law did not mean sacrificing my entire identity. And most importantly, I could love my family without abandoning myself.

And I learnt something else, something even more important.

My real empowerment began when I developed emotional intelligence and social intelligence. I learnt to understand people without losing myself in them, listen without absorbing everything, respond instead of constantly reacting and not every emotion around me belonged to me. And slowly, very slowly, I started coming back.

Today, when I think about that woman I was, I don't feel ashamed of her anymore. That one good step seeking support, helped me to **find the life that was still inside me**. And perhaps that is what healing really is.

Not becoming somebody new or erasing the past. But gently gathering all the scattered pieces and rebuilding oneself.

-Anonymous.

