MDDA-RI Matters
Newsletter of MDDA-RI
(formerly the Manic-Depressive and Depressive Association of Rhode Island)
“Best Of” Edition: Rally 4 Recovery
Providence, RI 2011

This is a special, edited compilation culled from previous distributions of the periodic newsletter of the MDDA-RI. For more information, please visit www.mdda-ri.org and/or join us at one of our weekly Tuesday night or bimonthly Saturday morning meetings.

Best Of: Support Group Topics

Weekly Discussions

Sleep
Sleep difficulties are a common problem. Sleep problems range from sleeping too much, not wanting to get up, not getting enough sleep, and not feeling like you need sleep. The Group has offered many solutions like:

- Go to bed at the same time and get up at the same time every day
- Set up a reward or something to look forward to, to help make it easier to get up
- If you can’t sleep, rest
- Take your night time medication in advance of when you desire to sleep
- Talk with your doctor about medication for sleep, or changing the time you take your medication
- Do something really boring until you get sleepy.

Stress
Stress was another big topic, in all of its forms. Many members expressed work-related stress and just as many expressed experiencing stress from not working. Holiday stress, family and relationship stress, and economic stress were all discussed. Strategies for coping with stress presented have included:

- Do less. Focus on one thing per day and take pride in getting that one thing done
- Manage relationships: be clear about how much time and energy you have
- Make sure you have at least one person you can talk with about the stress you are experiencing
- Keep your health care provider informed.

Working
Members discussed the stress associated with doing very many things; most prominently working or not working. It seems that both situations present challenges.

For working people, the Group suggested:

- Set reasonable limits with your employer on your availability
• Enlist the help of a coworker in getting “reality checks”
• Don’t answer your phone on days and nights off
• Keep the same routine on your days off: this will make it less difficult to regain momentum after days off or the weekend
• When possible, take a little time on Sunday night to prepare for the upcoming work week
• If you have disclosed your health condition, work with your employer on reasonable accommodations
• Really evaluate your capacity for either part time or full time work. There are times in our illnesses when working is just not the best option.

For non-working people, stress takes many forms.

For people who are job hunting, apart from a very difficult economy, stress is often located around whether or not to disclose to a potential employer. The wisdom of the Group on this topic is that the answer is highly variable and depends on circumstance.

For non-working people who are not job hunting, stress manifests in feelings ranging from boredom to guilt. Lack of structure, difficulty maintaining a sleep schedule, feeling like there is too much time to fill up, economic worries and feeling “less than” for being unemployed are some of the stresses mentioned by the Group.

Strategies for coping with not working include:

• Volunteer at something meaningful
• Reward yourself for getting up at a certain time every morning in order to maintain a better sleep schedule
• Exercise in order to reduce stress and get or stay fit
• Use medication prescribed by your doctor to combat intense feelings of anxiety or other difficult feelings
• Find or create a routine that consists of healthy lifestyle choices
• Try not to isolate: isolation tends to make things worse
• Work on self-acceptance and understanding that not working may actually be the wisest actual decision

As is always the case, each Group member had something useful to contribute on the topic of stress. Difficulty with stress is one of the universals associated with living (and working) with mental illness.

Thank you to Butler Hospital for their generous hospitality in offering us space for our Tuesday and Saturday meetings. Tuesday night meetings are from 7:00 p.m. to 9:00 p.m. on the second floor of the Ray Conference Center. Saturday meetings are from 10:00 a.m. to 12:00 noon every 2nd and 4th Saturday of the month, on the first floor of the Ray Conference Center on the Butler Hospital Campus.
Long ago, I was a case manager in one of our Community Mental Health Centers. I was well acquainted with mental illnesses and had the same low expectations for “chronicity” and “maintenance” that many of my colleagues held. I thought inside that box for years, until acquiring my own diagnosis and needing something more. I didn’t know it had a name, but I knew what it was when I first attended an MDDA-RI meeting.  

I have a theory. Let’s call it the “theory of diminishing expectations.” It goes something like this: you work with a provider for a while and attain a certain level of stability—not recovery—and that level is duly noted in your record and becomes your “baseline”: the level at which you are expected to function. Then, you are transferred to another provider and don’t quite meet that level. The new, lower, level is recorded as your baseline and you go on to the next provider. The next provider expects a lower level, and unless you exceed expectations, your level will appear to be declining. Basically, the system—with its high turnover rate and non-recovery orientation—traps people in a system of diminishing expectations. People don’t recover because no one expects them to.

Contrast that with MDDA-RI, where recovery is emphasized along with practical steps and know-how from peers. Certainly, MDDA-RI is no substitute for the formal treatment system, but it sure is complementary. Instead of “maintenance” and “chronicity”. MDDA-RI members expect change. Recovery is not the return to some previous way of being (although many new people come in hoping for that exact experience), it is the moving forward having consolidated the new experiences and new information contained in the experience of mental illness. It is living life fully with the life-changing experience that is mental illness. It is finding a new niche, discovering new strengths and abilities, applying a new measuring stick to progress and setbacks, making new adjustments in oneself and among others, and “finding one’s feet” in very fluid occurrences.

How do we get there?

I have another theory. “Support is to recovery as carbon is to life.” We get to recovery by being with others who are making the same journey, who have the same questions and uncertainties and the same need for reassurance that we are not alone. We get to recovery by asking “is this normal?” and hearing from others that the “abnormal” is, in fact, ordinary when you live with mental illness and that that is okay. We get to recovery when there are examples in the room of people who are just a little farther down the road than we are, just a little more hopeful than we are, just a little more settled than we are. We get to recovery with others. But we do the work of recovering ourselves. Having a group makes it easier and less lonely.
I am not fond of the word “recovery”. It implies too much that something was broken and is now fixed and I don’t think of any of us as broken people. I think we are extraordinary people living extraordinary lives which require extraordinary effort at times, bearing extraordinary rewards. Alternatives to “recovery” are words like “transformation”, “renaissance”, “recuperation”, “revitalization”, and “rehabilitation”. None of them quite capture the experience of the attitudinal and lifestyle shifts which take place when someone lives well with mental illness. And that is, after all, the goal for everyone.

MHCA/Oasis has a warm line for when you need someone to talk to in a non-crisis situation. Hours of operation are 4:30 p.m. to 9:30 p.m. Sunday through Thursday. The number is 401-529-7900.

My MDDA-RI Story
By Mike Sicard

Devastation. Newly divorced and back living with my parents. My Father’s cancer now spreading through him and knowing he was going to die. Myself newly diagnosed with metabolic syndrome and dealing with my own depression. Life didn’t seem like it could get any worse. Then my Uncle Sted died followed by my father and then my Aunt Dolly. I got so depressed I couldn't keep up with the things I needed to do at work. I lost my job and I had to be hospitalized. Life felt like it was all over for me. I couldn’t handle everything that was happening. After being released from the hospital I started in the Butler day program. After a week there I was informed my insurance wouldn't pay for any more time there so I was started at the day program at the Providence Center.

Through all this I had only a few constants in my life. My family, my friends and the MDDA of Rhode Island. Had it not been for these three things I don't know if I would be here today. Because of the support I got from all of the people at group and the help I had at home I made it through this trying time. Just as I was really getting my feet back under me my Mom passed away. It was three years later, but it had taken that long for the trauma to diminish and this threatened to undo all that I had accomplished. My doctor got me into his office that day and started an aggressive treatment of medication. My brother and his family kept me busy and as productive as possible. My friends from the MDDA rallied around me and helped to keep me sane.

Without the help and support of my friends at the MDDA, I don't know if I would have made it through these trying times. Being with a group of people who understood the myriad of emotions that were coruscating through me at this time and being complicated and amplified by my mood disorder brought me some peace and ability to cope.
Because of the encouragement and hope that the group was able to instill in me I was able to get through going on disability and having to move into subsidized housing with my dignity intact. The group process helped to get me through all the varied transitions that my life had to go through to get me to where I was headed. With all the bumps in the road and pain of the trip I managed to survive and thrive. I went back to work part time as an advocate for the Alive Program at NRI Community Services. I got to travel all over the country to conventions and on information gathering trips. I became a board member at NAMI-RI and went from a general board member to secretary of the board and finally to board Vice President. I am currently co-Vice President of the MDDA. The MDDA-RI has been a supportive force throughout my journey of recovery with my illness. It is because of many people from the group who I will not name here for confidentiality purposes that have kept me on the road to recovery and constantly looking for improvement to my life. I owe the people and the group all that I have and all that I am.

I was spectacularly unsuccessful. Much to the relief of my therapist and primary care doctor, I agreed to treatment. Dante’s dark woods, now, as they did back then, remain for me a powerful metaphor for how disruptive and disabling depression can be when left untreated.

Sixteen years later, poetry remains a solace (if solitary comfort) that uplifts and inspires me as I continue the process of discovering the myriad ways this mystifying illness gets in my way of living my life as fully I would like.

As Prozac lifted the weight of that first episode and I returned to my life, I found yet another poem, this one from the Greek playwright Aeschylus. With his words, I found some of the meaning of and purpose for that first descent into depression I had been searching for.

“He who learns must suffer. And even in our sleep pain that cannot forget falls drop by drop upon the heart, and in our despair, against our will, comes wisdom to by the awful grace of God.”

I have made several treks in and out of those dark woods now and I can safely say depression (along with and hundreds of hours of therapy) has made me wiser. It has certainly humbled me in ways that would have been imaginable during my small town Irish Catholic childhood and overactive, achievement-oriented twenties. My perspective on what constitutes a successful and purposeful life has changed. My
standards in every way have fallen - as they needed to. I like my own company far more than I ever thought possible and my priorities are crystal clear. As it reads on the headstones in the cemetery, “mother of, wife of, daughter of.”

Still, in midst of a fourth, officially deemed treatment resistant episode, it’s clear I have a great deal more to learn about living with this illness. And I do mean live. This time, as I make my way through the woods, I have acquired a group of awesome companions, as my children would say. Most of them have also been waylaid by a mood disorder. With their help and guidance, I have entered what I believe is the densest, darkest part of my woods where the biggest impediments to my healing reside. This is my abiding shame about having this illness and my chronic, misguided belief that if only I had the proper degree of strength, faith and fortitude I could make it disappear myself.

My fellow pilgrims are members of the bimonthly Saturday sessions of the peer support group sponsored by MDDA-RI. In our sunny room in the Ray Conference Center, on the lovely grounds of Butler Hospital, we tell our stories. We pass on hard-earned wisdom about medications and treatments to the newly diagnosed. We discuss light-boxes and alternative treatments. We help each other figure out when to push forward and when to step back and simply accept the limitations of illness. To family members who come seeking help for a loved one, we offer comfort, understanding and our knowledge of the resources available to them.

The life-altering importance of finding this group crystallized for me one morning this past winter. It was my turn to talk and I presented to the group my latest dilemma.

Tired of our depression-created social isolation, my husband had invited some of his co-workers to dinner at our house that evening. He promised to do all the work. Despite this, I was completely overwhelmed at the prospect of people coming into our home. To someone for whom simply taking a load of laundry down the stairs to the basement was a major achievement, what he was asking felt insurmountable. The house was a mess; the bathroom a disgrace and the kitchen floor beyond dirty. I knew even with his best efforts, the house would never become close to what I considered company clean.

To my surprise, no one told me to buck up and be a good wife - which is what I miserably had been telling myself. Instead, someone immediately piped up and suggested I spend the day at the movies; another advised going to a friend’s house until the whole thing was over. We laughed through my shame and tears.

The simple beauty of these Saturday morning gatherings is that my fellow mood-disordered colleagues get it. With them I don’t have the wearying task of trying to explain the unexplainable. And that morning, they accepted better than I could, the severity of my symptoms and limitations they created.

I am not out of the woods yet by any means. With the support of my MDDA group, I am, however, well on my way to finding a truly saner way of being in the world. I may not be able to make my depression go away, but I can get started on clearing away some of the thorny underbrush of shame along my path.

**MDDA-RI is a confidential, peer-run mutual support group. Our meetings are open to anyone with any psychiatric diagnosis, their friends and family members. There is no charge for attending meetings. For more information, please visit [www.mdda-ri.org](http://www.mdda-ri.org).**