Managing Your Recovery When You Have Mental Illness

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ILLNESS SELF-MANAGEMENT

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WHAT IS ILLNESS SELF-MANAGEMENT?

While there is no single agreed upon definition of illness self-management, most definitions converge on describing it as intervention designed to help individuals better manage their psychiatric illness. Using a broad definition such as this, most psychiatric rehabilitation approaches could be conceptualized as illness self-management. Many people prefer to define it more narrowly to refer to it as the management of the psychopathology of the disorder (symptoms, relapses, re-hospitalizations), but not necessarily all the associated impairments (work, social relationships), which then invokes the field of psychiatric rehabilitation. Note, however, that management of a psychiatric illness requires attention to social relationships (e.g., supports), involvement in meaningful activity, etc., so that effective illness self-management requires focusing on more than symptoms.

WHAT DOES ILLNESS SELF-MANAGEMENT INVOLVE?

The research literature on illness management identifies four different treatment components that were supported by the evidence:

1. psychoeducation about psychiatric illness and its management, which has been found to improve knowledge of the illness, but not to influence its course;

2. behavioral tailoring to address medication non-adherence, which involves helping people fit taking medication into their daily routines, and has been found to improve medication adherence *[Editor's Note: "Adherence" has replaced the old term "compliance"];*
3. developing relapse prevention plans, which have been found to reduce relapses; and
4. teaching coping strategies for dealing with persistent symptoms, which have been found to reduce symptom severity and distress.

These four treatment components are included in the illness management & recovery implementation kit (or toolkit), developed as part of the SAMHSA-sponsored evidence-based practices project. *[Editor's Note: SAMHSA: Substance Abuse and Mental Health Services Administration, a federal agency.]*

DOES ILLNESS SELF-MANAGEMENT HELP WITH SYMPTOMS? IMPROVED OUTCOMES? WHAT ARE THE POSITIVE EFFECTS OF ILLNESS SELF-MANAGEMENT?

Based on the research, the positive effects include reduced symptom severity and distress, and reduced relapses and re-hospitalizations. The illness management and recovery intervention teaches illness management skills in the context of helping individuals articulate and pursue personal recovery goals. This program is being disseminated in several states participating in Phase 2 of SAMHSA's implementing evidence-based practices project.

TAKING CHARGE OF YOUR TREATMENT

Patricia E. Deegan, Ph.D. & Associates, LLC

Editor's Note: The views expressed in this article are those of the author and do not necessarily represent those of NAMI Metropolitan Baltimore, Inc. We hope you find the article thought-provoking and helpful.

Meeting with a psychiatrist during "medication visits" is usually a very disempowering experience. Often the meetings only last for 15 or 20 minutes. During the meeting we are expected to answer a few perfunctory questions and to leave with prescriptions for powerful drugs that can dramatically alter the quality of our lives. In these meetings the psychiatrist assumes a position of power and we usually fulfill the expected role of being a quiet, unquestioning, passive patient. Subsequently we will be praised for merely being compliant or scolded/

punished if we fail to comply with prescribed medications.

Over the years I have developed a number of strategies for changing the power imbalance during medication meetings with psychiatrists. I would like to share some of these strategies with you.

STRATEGY 1: LEARN TO THINK DIFFERENTLY ABOUT MEDICATION

There are no magic bullets.

Recovery is hard work. No pill can do the work of recovery for me. If I sit back and wait for a pill to make me better, I will not get better. If I patiently wait for a drug to cure me I may become a chronic, helpless patient who swallows pills on command, but I will not recover. Recovery means taking an active stance towards the problems and challenges I face. *Recovery means changing our lives, not our biochemistry!*

Medications are only a tool.

Psychiatric medications are one tool among many other tools that I can use to recover. Physical exercise, eating well, avoiding alcohol and street drugs, love, solitude, art, nature, prayer, work, and a myriad of coping strategies are equally important to my recovery.

Using medications is not a moral issue.

There was a time when I thought using medications was a sign of weakness or that people who no longer used medications were better than I was. I no longer think this way. There is no right or wrong way to recover. What matters to me is taking care of myself in such a way that I have a chance to become the best person I can be. There are periods of time when I do not use medications and there are times when I do. It is a personal choice that I make.

Learn to use medications.

Today I do not simply *take* medications. Taking medications implies a passive stance. Rather I have learned to *use* medications as part of my recovery process. Learning to use medications within the recovery process means thoughtfully planning and following through with medication trials, medication reductions and/or medication withdrawal.

Always use medications and coping strategies.

There are many non-drug coping strategies that can help alleviate symptoms and distress. Take the time to learn strategies for coping with voices, delusions, paranoia, depression, obsessive thinking, self injury, flashbacks, etc. I have found that learning to use a variety of non-drug coping strategies helps to minimize the amount of medications I take or,

with practice, can actually eliminate the need for medications.

Learn about medications.

It is easy to feel intimidated by all the big words and technical jargon that get used about psychiatric medications. However, there are a number of ways that I have found helpful in getting reliable and accessible information about the medications I am considering using. I am careful to ask the psychiatrist I am working with about the medication she is prescribing. However, I often find this information insufficient. A great source of information is talking with other people who have used the drug. Perhaps the cheapest and easiest way to get more information is to ask a pharmacist who will give you a written fact sheet describing what the drug is supposed to do, what the unwanted effects are, and precautions including drug interaction information.

These drug fact sheets are written in non-technical jargon, but unfortunately leave out a lot of detail that might be important to you. If this is the case you can always ask your pharmacist for drug-insert information. The drug-insert information is essentially the same information that is contained in the Physicians Desk Reference (PDR). It is printed on a small roll of paper and inserted in the box of medications that the pharmacist receives. There is a lot of technical jargon in the insert but the information is more thorough than the fact sheet. In addition you can go to the library and use the Taber's Cyclopedic Medical Dictionary to look up words you are not familiar with. There are also a number of good books that can help you get answers to your questions. These include *Clinical Psychopharmacology Made Ridiculously Simple* (John Preston and James Johnson, published by MedMaster, Inc.), *Instant Psychopharmacology* (Ronald Diamond, published by W.W. Norton), *Toxic Psychiatry* (Peter Breggin, published by St. Martin's Press), *Natural Healing for Schizophrenia* (Eva Edelman, published by Borage Books, Eugene Oregon), or *Living Without Depression & Manic Depression* (Mary Ellen Copeland, published by New Harbinger).
"Manic Depression" is more accurately called bipolar disorder. Should this book still be kept in the line up?

If you have access to the internet, there are lots of resources including: Dr. Bob's Psychopharmacology Tips at http://uhs.bsd.uchicago.edu/~bhsiung/tips/tips.html, Healthtouch with an excellent database of over 7,000 prescription and over the counter drugs at http://www.healthtouch.com/level1/p_dri.htm or Medline at http://www.ncbi.nlm.nih.gov/pubmed/, or Soul's Self-Help Central at http://www.golden.net/~net.

STRATEGY #2: LEARN TO THINK DIFFERENTLY ABOUT YOURSELF

Trust yourself.

You know more about yourself than your psychiatrist will ever know. Begin to trust yourself and your perceptions. Sometimes I found it hard to trust my perceptions after being told that what I felt, thought, perceived, etc. was crazy. Part of recovery is learning to trust yourself again. Even during my craziest times there was a kernel of truth in all of my experience. If you are experiencing unwanted drug effects such as a feeling of apathy and indifference, constipation, loss of sex drive, double vision, etc., trust your perception. Don't let others tell you that such side effects are "all in your head". Check with the pharmacist or friends who have used the drugs, and check the books, internet, etc. Chances are that you are not the first person to have these drug effects.

It's your recovery.

Too often I have heard people say that "the drug made me feel better." Don't give all the credit to a chemical! Even if you found a drug helpful, look at all the things you have done to get well and stay well. A drug can sometimes open a door, but it takes a courageous human being to step through that door and build a new life.

Your questions are important.

Anyone who has been on psychiatric drugs for a period of time is probably going to ask themselves important questions.

- What am I really like when I am off these medications?
- What is the "real me" like now?
- Is it worth taking these medications?
- Are there non-drug methods I can learn to reduce my symptoms instead of using medications?
- Will I always have to take medications?
- Have my needs for medications changed over time?
- Do I have tardive dyskinesia that is being masked by the neuroleptics I am taking?
- There are no long-term studies on the medication I use. Am I at risk? Do I want to take the risk of not knowing the long-term effects?
- Am I addicted to these medications?
- Has long term use of these medications resulted in memory loss or decreased my cognitive functioning?

There is nothing "crazy" about having such questions.

What is unfortunate is that most mental health professionals do not recognize that these questions are to be expected. A recovery-oriented system would have detox centers and other supports available so that people could plan a rational withdrawal from medications in order to explore these important questions.

STRATEGY #3: THINK DIFFERENTLY ABOUT PSYCHIATRISTS

Most psychiatrists are too busy for <u>our</u> own good.

We would be wrong to assume that most psychiatrists have a thorough knowledge of their clients' treatment history. In an age of managed care, psychiatrists have less and less time to spend with more and more clients. Many psychiatrists have never read the full case record of the people they prescribe medications to. Even fewer could identify all of the various drugs and drug combinations that you have tried over the years and what the outcomes of those drug trials were. In light of this, I have found it important to begin to keep my own record of what medications I have tried, for what symptoms, at what dosages, and for what period of time. Whenever a psychiatrist suggests a new drug or a new dose, I always check my record just to be sure it hasn't been tried before. I don't want to repeat ineffectual or even harmful drug trials.

Most psychiatrists are trained in a test-tube point of view.

Most psychiatrists are trained to look at illnesses and symptoms. Most are interested in something called "symptom abatement" or getting rid of symptoms, usually through the use of medications. Most psychiatrists were never trained to view distress/symptoms in the context of people's lives. Thus they tend to look at our distress or symptoms from a 'test-tube point of view' and to ignore the context of our lives. For example, a psychiatrist might think he is doing a good job by giving lots of medications that finally result in "getting rid of" a person's delusions. From the test-tube point of view, the psychiatrist might declare this a success. But the person sleeps all day because she is on so much medication. It is true that the person does not have delusions anymore, but it is also true that the person barely thinks about anything at all and sleeps most of the time. When viewed in the context of the person's life the medications are unsuccessful. When we reclaim our power with psychiatrists, we must always remember to talk about our lives in context. We must not simply talk about our distress/symptoms as if we lived in a test-tube. I find it best to talk about my distress/symptoms in relation to my life. For instance, I might say that I am having trouble concentrating at work and that I want to continue to work, so I would like to know if

there are self-help strategies and medications that could help me achieve better concentration.

Psychiatrists often have conflicting interests.

It would be comforting to think that psychiatrists were serving our individual interests. But this assumption would be naïve. Many psychiatrists complain of the competing interests that tear at the ethical fabric of their practice. Especially if I am working with a psychiatrist who is part of a managed care system, I feel it is important to ask what, if any, caps on services she is working under. In other words, some psychiatrists receive their paychecks indirectly from managed care corporations that require them to prescribe one type of drug rather than more expensive types. If this is the case, we should have this information!

Sometimes psychiatrists are wrong.

Most psychiatrists do not encourage us to seek second opinions regarding diagnosis, medications, or other somatic treatments like ECT. However, at certain times I have found it important to seek out a second opinion. Even with a managed care plan or if you are on Medicaid or Medicare, it is possible to get a second opinion on an issue you deem important. It can take a lot of work, phone calls and even a friend to help advocate, but it can be done and you are worth it!

Psychiatrists are not experts in everything.

Most psychiatrists believe in the primacy of biology. Most have a mechanized and materialist world-view. Thus, chances are that if you have a diagnosis of major mental illness and you talk to your psychiatrist about ecstatic spiritual experiences, mystical experiences, psychic abilities, etc., these will be perceived as crazy or symptomatic. One way of taking back your power is to recognize that you have control over what you share with a psychiatrist and what you choose to keep private. A meeting with a psychiatrist need not be a confession! Talk with mystics about your mystical experiences. Talk with psychics about telepathy, etc.

STRATEGY #4: PREPARE TO MEET WITH YOUR PSYCHIATRIST

Set your agenda for the meeting.

I have found it important to set my agenda for a meeting with a psychiatrist rather than simply reacting to what he does or does not do. In order to set an agenda it is important to define your goals. For instance a possible goal might include wanting to go to work and discussing a medication change that would support your personal work plans. Another goal might be wanting to have a baby and discussing your plans and related medication changes with your psychiatrist.

Other goals for a meeting with a psychiatrist might be planning for a medication reduction, planning for a medication withdrawal, checking for tardive dyskinesia, finding a solution for unwanted drug effects, or reporting on a medication/self-help trial. Try, if possible, to set one goal for each meeting.

Organize your thoughts and concerns.

I have found it important to prepare ahead of time for a meeting with a psychiatrist. I have developed a form that helps me organize my thoughts and to put things in writing. You will find a copy of this form at the end of this paper. (See p. 14)

Always talk about your life, not just your distress/symptoms.

You do not live in a test-tube! Be sure to talk about what's important in your life right now and what your plans for the future are. Tell your psychiatrist about the things that make your life worth living.

Don't settle for medication effects that rob you of the capacity to feel joy, passion, to work, to volunteer, to have friends, etc.

Be specific.

The more specific we can be about our concerns, the more control we can exercise during a meeting with a psychiatrist. For example, if a psychiatrist begins a meeting by asking, "How is that new medication working?" a vague answer would be "Oh, it's helping a little I think." Imagine how empowered you would feel if, instead, you were able to answer, "Well, before I began this medication trial I was so depressed that I missed seven days of work, spent 14 days in bed and lost 3 pounds. But during the last two months, since starting the drug and using the new coping strategies, I have only missed 2 days of work, have regained the weight I lost and I have only spent 4 days cooped up in my apartment." Notice how this level of specificity puts you squarely in the driver's seat of your life and positions the psychiatrist as a co-investigator, as opposed to being the authority over your life. Getting this specific may sound difficult, but it is not. It simply requires that you learn how to record your medication and/or self help trial on a daily basis and that you summarize this information before seeing your psychiatrist.

Write your questions down.

Write your questions down before seeing your psychiatrist. Bring the questions with you to the meeting. My experience is that these meetings can be stressful and that having my questions written down allows me to relax a bit. If you are considering trying a new medication, be sure to ask the following questions:

- Exactly how will I know if this medication is working for me?
- How long before I should start to notice an effect from this medication?
- What are the unwanted effects or side effects associated with this drug?
- If I should experience unwanted effects or side effects, what should I do about it?
- How can I contact you if, during this medication trial, I have questions or concerns I want to check out with you?

Role-play.

Sometimes it can be helpful to role-play with a friend or someone you trust before seeing your psychiatrist. Learning to talk to a psychiatrist from a position of personal power is a skill that can be learned and must be practiced. Be patient and give yourself time!

STRATEGY #5: TAKE CHARGE OF THE MEETING

Bring a note pad and pen to the meeting.

Most of us have had the unnerving experience of talking to a psychiatrist while she busily jots notes that we never get to see. Bringing your own note pad and pen, and taking your own notes is a good way to break the habit of being a passive patient. It gives you something concrete and active to do while in the meeting. Writing notes can also help you remember important points.

Tape-record the meeting.

I can get very anxious when meeting with a psychiatrist and thus a lot of information passes by me. I have tape-recorded meetings so that I can listen to them afterwards and pick up on the information I may have missed. I have always asked permission before recording. Although some psychiatrists don't feel totally comfortable with the idea (they fear lawsuits), all have agreed to it when I explain why I am taping the meeting.

Announce your agenda at the beginning of the meeting.

If you have done your meeting preparation work, then you know what you want to get out of the meeting with your psychiatrist. There have been many times when I literally bring a one page, written statement of my agenda, concerns, observations, etc. to the meeting. I hand a copy to the psychiatrist and begin the meeting by reading my statement out loud. My experience has been that most psychiatrists initially object to my starting this way. They are accustomed to starting meetings with their

own agenda, which is usually vague and centered on the notion that they will observe me for significant clinical signs and symptoms while I answer their questions. But if I insist on beginning the meeting with my statement and assure them they can talk later, I find they soon come to understand the value of my preparation. In fact, some of the psychiatrists I work with keep the copy of my agenda and statement and add it to the clinical record. A sample copy of an opening statement can be found at the end of this paper. (See pg. 12).

Bring a friend or advocate.
Many people bring a friend or support person when they see a dentist, have a physical exam, etc. It makes sense to bring a friend to a meeting with a psychiatrist, especially when you are first breaking out of the role of passive patient and are learning to reclaim your power.

These strategies have worked for me. Together, these strategies have helped shift the balance of power between me and the psychiatrist I am working with. Perhaps some of these strategies will make sense to you. I am sure that you will come up with your own strategies as well. What is important is to realize that you can take your power back and become the director of your own recovery and healing.

PREPARING TO MEET WITH MY PSYCHIATRIST

Patricia E. Deegan, PhD

(this is a form you can use to prepare for appointments with psychiatrist or nurse specialist. Also helpful to fill out with someone you trust (friend, relative, peer counselor, advocate, counselor, therapist or case manager)

1. List the things in my life that are important to me and that give my life meaning (work, friends, reuniting with my husband, going for walks in nature, staying up late to watch a favorite TV talk show, reading at the public library, using the computer, etc.)
2. List the things that I plan on doing in the near future (getting a job, dating, volunteering, getting my kids back, finishing school, getting pregnant, etc.)
3. What do I want to accomplish during my next meeting with my psychiatrist? What is my goal for the meeting?
4. Describe the distressing experiences or "symptoms" that are bothering me. How does it affect my life, especially those things I listed in questions 1 & 2. If nothing is bothering you, state that.
5. Sometimes other people are more upset than me about my distress or symptoms. What concerns other people about my distress or

symptoms? How might their concerns affect my life? For instance, if my neighbors call the police because I am shouting at night, I could end up in trouble with the law or back in a mental hospital. How might that affect what I wrote in questions 1 & 2?

6. Does this distressing experience or symptom affect:
[write: YES; NO; or N/A if not applicable]

my relationships/friendships? ____

my ability to work? ____

my ability to live where I want to live? ____

my ability to take care of myself? ____

my ability to do the things I enjoy in life? ____

my ability to be the person I want to be in life? ____

my self esteem? ____ my health? ____my safety? ____

my ability to participate in programs or groups which might help me in my recovery process? _____

other things not listed above?_____ (Describe)

7. Is this a "symptom" I can live with at this time, or do I want to try to do something about it? (check one)

____ Yes, I want to do something about it.

____ No, I can live with this symptom.

____ I can live with this symptom but others around me find it too disruptive and so I feel I have to change or eliminate it.

____ I can live with this symptom and even though others find it too disturbing, I do not want help to change or eliminate this symptom at this time. The consequences of this choice may be: _____

8. Has anything other than medications ever helped in the past with this distressing experience or symptom? Examples might be meditation, therapy, exercise, artwork, acupuncture, diet changes, lowering my caffeine intake, stopping taking street drugs or using alcohol, etc.

____ Yes ____ No

If "yes," describe these non-drug coping strategies:

9. If I haven't used self-help coping strategies in the past, are there any I can think of that might help? ___Yes ___ No

If "yes," describe: _____

10. Have any medications in the past helped you with this distressing

experience or symptom? ____ Yes ___ No.

If "yes," list those medications and any dosages you can remember:

_____

A Guide To Writing Your Opening Statement To Your Psychiatrist

Take charge of your meeting by preparing an opening statement that expresses your agenda and what you want to get out of the meeting. Use these questions to organize your statement.

1. Describe the distressing experience(s) or symptom(s) you want help with. Be specific and remember to state how your distress/symptoms are affecting what is important to you in your life.
2. When does this distress/symptom occur *e.g.*, mostly at night, in the morning, after eating, in social situations, only when I am alone, after seeing my family, etc.?
3. When, if ever, does this distressing experience(s) or symptom(s) *not* occur?
4. How often does this experience(s) or symptom(s) occur *e.g.*, every day, five times a day on average, once a week, all the time, only when I'm anxious, it seems to vary and has no specific pattern, etc.?
5. What are the non-drug coping strategies that have helped with this distress or symptom in the past?

Sample Meeting Agenda Statement

After preparing for your meeting with a psychiatrist, you have written a statement about your concerns and what you want help with. You arrive at the meeting with pen and paper, a tape recorder and/or a friend. You give the psychiatrist a copy of what you have written and then say, "I am going to read this to you. Please hold your questions until I am done."

"Today I am concerned about how scared I am feeling. For the past three weeks, ever since I broke up with my boyfriend, I hear people talking about me and saying I am a loser. I hear them talking behind doors but if I check, there is nobody there. But I hear it and then I get really scared. It doesn't happen when I'm busy such as when I am working. It seems to happen mostly at night when I am alone or when I'm in a big place like the mall. Last night I made sure to count how many times it happened and I heard people calling me a loser seven times. Finally, I made myself go to bed and eventually I fell asleep but that was hard to do.

This has happened in the past. Last time I lost my job because I was so

freaked out about people saying I was a loser. This time I don't want to leave my job. I like the money I make on my job. I also want to try to get back together with my boyfriend. That's important to me also. Cutting down on coffee in the evening helped the last time this happened. Also staying busy helped. My friend said maybe I am upset about losing my boyfriend. I think talking to a therapist about that might help. I think medications would help, too. Do you think there is a medication that might help me be less anxious and that will also help me keep my job and get together again with my boyfriend?"

After reading your opening statement to your psychiatrist, listen to their comments and take notes. Discuss a medication/self-help trial and be sure to ask the questions listed below:

1. Exactly how will I know if this medication is working for me?
2. How long before I should start to notice an effect from this medicine?
3. What are the side effects of this drug?
4. If I should experience any of these side effects, what can I do about them?
5. How can I contact you if, during my medication trial, I have questions or concerns I want to check out with you?
6. How long should my medication/self-help trial last?
7. When is my next appointment?

On the next page you will find a sample medication/self-help trial worksheet. Make copies of this worksheet and fill it out each day until you meet with your psychiatrist the next time. In preparing for that meeting, look at your chart. Do you see trends or patterns during the trial? Is the frequency of the distressing experience changing—getting better of worse? Have you been taking the medications as prescribed and are you using the self-help strategies? Are there more strategies you can think of or have researched that should be added at the next meeting? How long before I should start to notice an effect from this medicine? What are the side effects of this drug?

MEDICATION AND SELF-HELP TRIAL WORKSHEET

Date	Did I take my new medica-tiomn today?	Did I do my self -help strategy today?	How often did my distress/symptom occur today?	Was my distress/ symptom worse, somewhat better, or much better today?	Any unwanted drug effects?	Am I able to do the things I find important in my life? How does the medi-cation affect these?

RECOVERY – A CHANGE IN STYLE OF LIFE

Maxine Cunningham, NAMI Peer-to-Peer graduate

Despite the medications, despite the therapy, and despite the support of family and friends, there are still days when I experience crying spells, days when it is difficult to get out of bed, and days when I fight panic attacks that can be life threatening. But, I am hopeful and I feel victorious. Denial is the biggest challenge; self-discipline is my principal antidote for good mental health. I now have a plan – a relapse prevention plan that I developed as a student in the NAMI Peer-to-Peer Recovery Education Course.

- I have daily devotions – prayer, Bible study, "journaling," reading inspirational books.
- I work in my church and in my community.
- I am writing a book of poems entitled *Walk and Not Faint*. Maxine has come out with several books. Do we want her to update this story?
- I am learning more about my mental illness. I have become a vocal advocate for the acknowledgement and understanding of mental illness among my family, my church, and my friends and people that I meet.
- I surround myself with positive people.
- I exercise and I rest.
- I visit with my plants – T'vine, Nia (Purpose), Kujichagulia (Determination), Courage, Umoja (Unity), Harambee (Togetherness), Ujima (Collective Responsibility), and M'dear so that I am reminded of who and whose I am.

In extraordinary ways, this illness has brought me blessings. Each day becomes a celebration because, in the words of Lucille Clifton, "Yesterday something tried to kill me and failed."

CONSUMER'S CORNER

Darla Guy, NAMI C.A.R.E. Facilitator, Peer-to-Peer Mentor

Wow! Do I dare believe what I'm reading; there *is* a path to Managing Your Recovery. Inside this issue of NAMI-News I am staring at the phrases "…Self Management", "Reclaiming Your Power…", and

"Wellness Tool…" Phrases that make me sit up straight and take notice to what's being said. The feeling of empowerment just wraps around me. As individuals with a mental illness, we so often get the message that "we can't." Now I'm not only being told I can, but how. Amazing!

We *can* talk to our psychiatrists as self-empowered adults? To some of you this may not be a new behavior. But to me and many others, talking to the psychiatrist causes dry mouth, tremors, headaches, mumbling or stuttering, and so on. Of course, let's not forget how inadequate this can make one feel.

I'm sure that the people who know me are surprised to hear me include myself in this group, because I am normally a well-spoken, open, and confident person. Well, let's get real, a psychiatrist is in a position of authority and power over me, right? This makes me want to run and hide. I bet many of you want to hide with me. Well, hide no more. I want to feel empowered.

We *can* think and feel differently about ourselves. We don't have to listen to that old recording going round in our heads and hearts. We can have new healthy words and phrases in our heads. If we speak well of ourselves others will follow. I can trust myself again. I want to be empowered.

We *can* learn to manage our illnesses and use our medications as tools. Each day we can strive to learn one more thing. Education is power. I want to soak up the knowledge that will help me manage my life. I will be empowered.

As a Peer-to-Peer Mentor and NAMI Connection support group facilitator I hear a lot about relapse prevention. Relapse prevention, in my words, is basically the ability to look backward at what you've already tried to see how to change tomorrow's efforts. It's not a simple process, especially without feeling empowered. Empowerment can begin with a small step, like reading about your medication. Try not to let it stop there.

Maybe your next step is to join others and me at one of the NAMI Connection support groups. Share your empowerment and relapse prevention tips or be the one who learns from the tips.

With NAMI's help and your empowerment, Managing Your Recovery can be in your future. It's in mine.

WELLNESS TOOL:
Changing Negative Thoughts to Positive Ones

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Check out Mary Ellen Copeland's Copeland Center for Wellness and Recovery website at www.copelandcenter.com. The Center publishes the Mental Health Recovery Newsletter quarterly. This newsletter is available free to anyone either by e-mail or the postal service. If you would like a subscription, you can order it through the website.

You may have difficulty with troubling thoughts and feelings. I know I do. I've discovered they don't do me any good. In fact they make me feel much worse. Having more negative thoughts and feelings is, for me, an early warning sign that I might be getting depressed. I've learned some tricks that help me get rid of these negative thoughts. When the negative thoughts are gone, or at least I don't have as many, I feel better.

Negative thoughts or messages are often very specific things I say to myself, like "*I am a jerk,*" "*How could you be so dumb?*" or "*You are just a loser*." They are often short, like "*Stupid*" or "*Idiot.*" I tend to believe them no matter how untrue they are. I find myself repeating them to myself in my mind very quickly, without thinking, over and over again. Sometimes they include words like *should, ought,* or *must.*

From what I have learned in all my years of talking to people who have mental health difficulties, each person has her or his own negative thoughts. Everyone says these thoughts are hard to turn off. They may include:

- self-doubts such as, "I'm not smart enough to go to college," "I am not creative," "I am not likable," or "I am not good at anything."
- irrational fears of specific objects or situations, which seem unreasonably frightening, like snakes, spiders, crowds, heights, airplanes, and darkness.
- making assumptions about how others feel without really knowing.
- expecting the worst will happen.
- continually comparing yourself unfavorably with others.
- feeling that you are personally responsible for everything.
- thinking everything must be fair or equal.
- believing everything you feel must be true.
- assuming your happiness depends on the actions of others and that if they would change, things would improve.
- making someone else responsible for whatever is going badly.

- expecting never to make mistakes, to always be perfect.
- having a rigid set of indisputable rules about how everyone should act including yourself.

The first step for me in getting rid of these thoughts, was to make a list of my negative thoughts. Unfortunately, when I first began doing this, my list was very long. Now, because I have been working on it, my list is much shorter and I don't have to work on it so much.

It helps me to analyze my negative thoughts by asking myself if these negative thoughts are really true, and if a nice person would say this to another nice person. If my answers are no, then I ask myself why I should be saying it to myself. Sometimes I ask other people that I like and trust if my negative thoughts are true. For instance, I might ask my daughter, "Is it true that no one likes me?" Perhaps most important, I ask myself, "What do you get out of saying this to yourself? How does it help? How does it hurt?" By this time I usually realize that this thought is not at all helpful, and it is making me feel badly.

Then I work on developing positive things to say to myself to replace these troubling thoughts. In developing these positive responses to negative statements, I avoid using negative terms such as *worried, frightened, upset, tired, bored, not, never, can't*. I don't make statements like *"I am not going to worry any more."* Instead, I say something like *"I will focus on the positive."* I use only positive words like *happy, peaceful, loving, enthusiastic, warm.* I substitute *it would be nice if* for *should.* I always use the present tense, for example *"I am healthy," "I am well," "I am happy," "I have a good job,"* as if the condition already exists. And I use *I, me,* or *my own name.*

Some of my most common ones are:

- **Negative thought:** I will never feel good again. **Positive Response:** I feel great.
- **Negative Thought**: I am not worth anything. **Positive Response**: I am a valuable person.
- **Negative thought:** It is not OK to make mistakes. **Positive Response**: It is OK to make mistakes.
- **Negative thought**: There is no reason for me to go on living. **Positive Response**: There are many reasons why I should live.

Troubling thoughts have often become so familiar that change takes persistence, consistency and creativity. It takes several weeks to several months of replacing the troubling thought with a positive response to effectively change it.

You may want to spend some time each day, maybe right after you get up or before you go to bed, working on reinforcing your positive statements by:

- repeating them aloud or to yourself over and over.
- writing them down over and over again--10 or 20 times.
- asking someone you trust to read your positive responses to you.
- making signs which say the positive response to post in obvious places around your home and then reading them to yourself every time you see one.
- making a tape of your positive thoughts that you can listen to over and over, or every time the negative thought comes up during the day, say, "stop" to yourself, visualizing a big red stop sign, then repeating your positive response several times.

HOW TO GET A GOOD NIGHT'S SLEEP:

From the NAMI peer-to-peer recovery education course

Kathryn McNulty, NAMI Peer-to-Peer Recovery Education Course. Copyrighted. Reprinted with permission. ***Has this been updated?***

There, that is our secret: go to sleep! You will wake, and remember, and understand. Elizabeth Barrett Browning

One thing that nearly all people with mental illness experience is some sort of sleep disturbance. Sleeping too much, too little, sleeping too lightly, frequent awakening, a chronic feeling of exhaustion, inability to get a "good" night's sleep, inability to get out of bed, a feeling of being "revved" after remarkably little sleep and no need for sleep whatsoever, are some of the most common things people with mental illness say about their sleep.

Whatever "flavor" of mental illness we have, it is almost a certainty that some trouble with sleep comes along with the territory. And very often, very subtle problems with our sleep patterns are the very first sign there is something not quite right; and that we are out of harmony in some way that may lead to trouble. And as often as sleep trouble can be the first sign that something is wrong, a sleep disturbance may also and equally cause something to go wrong.

One of the most misunderstood aspects of living with these chronic health problems is that they are exhausting. Most people with mental illness – regardless of diagnosis – feel extremely fatigued during the earliest parts of recovery from an acute episode.

It is also not uncommon to struggle to feel adequately rested during calm periods with our illnesses. It is not unusual for people to feel tired for months, and it is also not unusual for people to not recognize that they are tired.

We are often encouraged to live "as normal a life" as possible, and the demand that places on our innate energy levels is not universally well understood (nor is it universally true). We often find ourselves "going through the motions," trying to keep our lives as stable as possible and live up to what is expected of us, without really counting the energy cost to us.

Staying well rested is a key ingredient in the recipe for health, and this is especially true for people with mental illness.

HOW TO GET A GOOD NIGHT'S SLEEP:

- Go to bed at the same time every night and get up at the same time every morning every day of the week.
- Do not get attached to late night TV no matter how excellent the shows are, even if you have cable TV.
- Do not give in to the temptation to change your sleep schedule on the weekends. Yes, we know this is cruel but it is crucial.
- Do not sleep during the day to make up for a bad night's sleep the night before. Tough it out, and let your body clock reset itself naturally.

Step 1, Getting to Sleep:

- Take your night time medications, as prescribed, enough time before you want to sleep so your meds work for you.
- Limit your intake of caffeinated beverages (coffee and soda) during the day. It is a really good idea to stop taking caffeine in the middle of the day.
- For some folks, waking up to urinate can disturb a sleep pattern. To avoid this problem, limit liquids for about 3-4 hours before bedtime, and make sure you empty your bladder before bed.
- Make sure the room you sleep in is cool enough if you like to sleep in the cold, hot enough if you like to sleep in heat, or whatever temperature you find desirable. Some folks find they sleep better with a window cracked open slightly, even in the winter months, to let fresh air into the room.
- Some folks find that reading puts them to sleep. Some folks fall asleep listening to music. Some folks find that arranging their body

into the position they sleep in lulls them to sleep (the body remembers). Some folks find that warm milk or a tuna fish sandwich helps make them sleepy, since these foods are naturally high in l-tryptophane, a natural soporific.

- Many folks find a "ritual" helpful in getting to sleep. Following the same pattern night after night can be very helpful (and sleepy-making) for some folks.
- If you have the luxury of the space in your home, reserve the bedroom for sleeping. The more out of the habit of watching TV, or studying, or engaging in hobbies in the bedroom we become, the more likely we are to associate our beds with rest.
- **Don't forget to set the alarm!**

Step 2, How to stay asleep:

- Some folks have a tendency to wake frequently and watch the clock all night long. If you are going to continue to do this, you really have to train yourself to notice the time and not judge it. Just notice the time and remind yourself you can go back to sleep.
- For other clock watchers, turning the lighted dial on the alarm clock around – facing away from them – solves the problem.
- Don't smoke in the middle of the night! Those who smoke are likely to awaken themselves quite fully in order to smoke safely, and this can make it very hard to return to sleep. Forego the middle-of-the-night smoke.

Step 3, How to wake up:

- When the alarm goes off, get up! Some people find putting the alarm clock across the room – making it so they have to get out of bed to shut it off – helps.
- Some folks find it really helpful to leave the blinds or curtains open so that the brain is awakened gently by the sun coming into the room, before the alarm actually goes off and fully wakes them up.
- Some folks find that setting aside a special reward, or having something to look forward to, helps them to accomplish the goal of getting up in the morning.
- Something else that may help is to remember that while it may be agony to get up a good bit earlier than we want, the process of resetting the body's clock takes only 2-3 weeks ... and as we get on a more regular schedule, this will **not** be so difficult!

TOTAL WELL-BEING INSIDE AND OUT

Excerpted from NAMI's Hearts and Minds Program with permission.

"Wellness is a mind and body thing. I don't think you can separate them. If I'm doing well mentally but going to a lot of doctors for other ailments because I'm 60 pounds overweight, that's not wellness."

- Jane, 48, bipolar disorder ***Is this the most updated account?***

FEELING GOOD FEELS GREAT!

Living a healthy lifestyle has many benefits—not all physical. When everything is working together—when your body and your mind are strong—you have more energy and self-confidence and can take more control of your life.

For people who live with mental illnesses, a healthy lifestyle is especially important. Sometimes, it is easy to become so focused on treating a mental illness that physical health is neglected. But having a healthy body contributes to emotional recovery.

Eating the right foods, exercising, finding ways to manage stress, getting enough rest and having friends and activities that you enjoy are all part of healthy living. It can help you make better choices for yourself, develop new interests and even make new friends and acquaintances, leading to a happier, more fulfilling life.

But Where Do You Start?

Balance is one of the most important things to remember when you make decisions about your diet, exercise, work and social activities. Too much of anything—even things that are good for you—is not healthy. But when you have each of these things in balance—in the right amounts for you—you will be better able to manage your life and your recovery.

Your case manager or primary-care physician can help you develop a total care plan that not only nurtures your mental health but also deals with blood pressure, diabetes, healthy weight, exercise and overall good physical health. Having a "buddy," someone who has many of the same goals as you, can also be helpful.

Some days you just won't feel like exercising. Other times, a box of cookies may seem like the solution to a particularly stressful day at work. A friend or buddy can help you stick to your diet and exercise program. You can also help them by encouraging them to stay on track if they start to slack off. Having a partner can make something that seems difficult a little more pleasant. It's a great way to start friendships, too.

Making Time to Be Healthy

Planning a regular routine is another important part of your health and wellness program. Scheduling your activities can help you keep track of your time and reduce stress by giving you more control over your day. It helps you set and achieve your goals, increasing not only your physical well-being but your self-confidence as well.

Of course, nothing is perfect. Things often come up that get in the way of your plans. When that happens, a schedule can serve as a guide to help you get back on track and continue to do the things that are good for you. When deciding how to plan your routine, include all aspects of your treatment program. It is important that you include doctor visits, support group meetings, and your medication schedule. Planning a weekly menu can help you make healthy choices that won't interfere with your medications or budget. Adding even moderate exercise to your routine will help you feel good and manage your weight.

Finally, be sure to schedule a regular bedtime. You need to get enough rest to function at your best. Many people find the best way to do this is to go to sleep and wake up at the same time every day. If your medications make you tired, talk with your doctor about the best times to take them to fit in with your sleep schedule. *[Editor's Note: See more about getting sleep in the excerpt from Peer-to-Peer Recovery Education Course starting on p.19]*

REST ASSURED . . . SLEEP APNEA CAN BE CURED

If you stick to a regular bedtime but still wake up tired and not yourself, you might be suffering from a condition known as sleep apnea. Sleep apnea can ruin a good night's sleep by interrupting your breathing.

You won't fully wake up, but stir just enough to start breathing again. However, this disturbs your sleep cycle and the damage is done—it's another night with interrupted sleep and another day when you are not functioning at your best. Because people with sleep apnea often snore, your partner's sleep could be affected, too!

If you have the following symptoms, talk to your primary-care doctor about getting a thorough evaluation:

- Snoring, especially loud snoring.
- Daytime sleepiness.
- Irritability.

Left untreated, sleep apnea can cause high blood pressure, depression, memory problems, impotence, weight gain, headaches and cardiovascular disease. It can also affect your job performance and make driving

especially dangerous.

Although sleep apnea can affect anyone, being overweight is the primary risk factor. Smoking or using alcohol also puts you at higher risk. Men and anyone over the age of 40 are at increased risk. There are several treatment options for sleep apnea, so check with your doctor about what's best for you.

METABOLIC SYNDROME: A PREVENTABLE WARNING SIGN

In the last few years, doctors and researchers have come to understand that certain risk factors appear together and predict heart disease in many people. Metabolic syndrome is identified by a group of risk factors common in heart disease and diabetes.

Someone with three or more of the following symptoms is at high risk for metabolic syndrome*:*

- Obesity that is centered in the abdomen. A quick rule of thumb to identify obesity is having a waistline more than 40 inches in men or more than 35 inches in women.
- High triglycerides, LDL (bad) cholesterol.
- Low levels of HDL (good) cholesterol.
- High blood pressure (130/85 or higher).
- High glucose levels (as measured by a "fasting" glucose test).
- Insulin resistance.

The good news is that by consulting with your doctor and making small changes in your lifestyle, you can slow down or even reverse the impact of this syndrome. Your doctor can help you find the right medications to prevent damage caused by obesity, high blood pressure, diabetes and heart disease.

Here are some things you can do to help yourself stay healthy:

- Watch your weight. If you are overweight, make changes in your lifestyle and diet to get to a healthy weight.
- Change your diet. Carbohydrates, especially the kind found in cakes, cookies, and crackers, can wreak havoc with blood sugar levels and increase your weight, so limit your intake.
- Increase your exercise. A little exercise goes a long way in warding off diabetes and cardiac disease. Just walking 20 minutes a day can have results.
- Work with your doctor to monitor your blood pressure and glucose levels.

NAMI PROGRAMS:

FOR FAMILIES & CAREGIVERS

- **NAMI Family-to-Family**: a free 12-session course for relatives and significant others of individuals with severe mental illnesses. The course discusses the clinical treatment of these illnesses and teaches the knowledge and skills that participants need to cope more effectively.
- **NAMI Family Support Groups**: a 90-minute weekly peer support group for relatives and significant others.
- **NAMI Basics:** an education program for parents and other kinship caregivers of children living with mental illnesses.
- **NAMI Homefront:** an education class for families, partners, and friends of military service members and veterans experiencing a mental health challenge.

FOR INDIVIDUALS WITH MENTAL ILLNESS

- **NAMI Peer-to-Peer:** a free 10-session course for individuals with mental illness containing individual relapse prevention planning, a debriefing/storytelling week and an advance directive for psychiatric care.
- **NAMI Connection Recovery Support Group:** a 90-minute weekly support group run by persons who live with mental illness for other persons with any diagnosis who also live with mental illness.

FOR PROVIDERS, THE GENERAL PUBLIC & ADVOCATES

- **NAMI Ambassadors:** a variety of workshops for community and professional audiences presented by relatives and individuals living with mental illness about: Basics about Mental Illness, Working with Families in Crisis, Children with Behavioral Disorders, What is Recovery? And others.
- **NAMI In Our Own Voice:** a 90-minute interactive, multimedia presentation by individuals with mental illness that offers hope and provides insight into the recovery now possible for people with mental illness.
- **NAMI Smarts for Advocacy:** a hands-on advocacy training program that helps people living with mental illness, friends and family transform their passion and lived experience into skillful grassroots advocacy.

The foregoing programs are available across the state of Maryland. Check with your state or local NAMI to determine which programs are available in your area. To locate state or local NAMI organizations nationwide, or to receive information from the national NAMI helpline or website, call (800) 950-6264 or go to www.nami.org.

To order additional copies of this booklet, please contact
NAMI Maryland at 410-884-8691,
info@namimd.org,
or visit www.namimd.org.

To locate state or local NAMI organizations nationwide, or to receive information from the national NAMI helpline or website, call (800) 950-6264 or go to www.nami.org.