Appendix 4
Suggested Readings for
Chapter 4: Symptom Management

New Partnerships for Women

PSYCHOLOGICAL OR EMOTIONAL SYMPTOMS*

Beginning Ritual

To begin work on this topic, write four good things that happened to you in the last two days:

_____

_____

_____

_____

Experiencing Symptoms Caused by Abuse

If you were abused, you probably developed certain symptoms in response. The symptoms may have happened right away or, in some cases, months or even years after the abuse.

Some symptoms, such as fear, anger, or sadness, are obviously connected to the abuse. Other symptoms, such as paranoia, dissociation, or panic attacks, may have caused a bit more confusion for you. The feelings and behaviors may have been so upsetting and overwhelming at times that you felt as if you were going crazy. In fact, all of these symptoms were signs that abuse had occurred. Some were immediate responses to the abuse, others were attempts to cope with the abuse and prevent it from happening again, and still others were ways to deny that it had ever happened at all so that you could go on living.

As you begin to think about your symptoms differently, it will be up to you to decide what you want to do about particular feelings and behaviors. Some you will want to control yourself, some you will need help from medication or counseling to control. Some symptoms will be easy for you to let go. In other cases, you might decide to hold on to a symptom for a while, in case you need it.

Many signs of abuse have been mistaken for symptoms of mental illness or biochemical brain imbalances, such as chronic depression, bipolar disorder, manic depression, or schizophrenia. If you've sought help from health care providers,

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perhaps you were told that your symptoms were signs of a disease or a mental illness instead of being the markers of abuse. You may have been given a diagnosis and some medication and never even asked about your abuse. It may be tempting to focus on one view of the problem, but when you see your emotions, biology, and everyday experiences as part of an integrated whole, your recovery will make more sense to you.

Some traumatized women receive treatment at mental health clinics for years for symptoms of anxiety, withdrawal, and dissociation, receiving diagnoses of major depression, bipolar disorder, and borderline personality disorder. Meanwhile, the underlying problem is ignored. Rather than help, diagnoses that obscure the role of trauma just make many women feel bad about themselves. When a woman begins to see her symptoms as connected to years of physical and emotional abuse, she may feel an enormous sense of relief, as if a cloud of confusion had lifted. She may also, however, feel sad and angry because her underlying problem—the trauma—was never really treated.

In this topic, some of the symptoms and feelings associated with abuse will be described. (Addictive and compulsive behaviors will be addressed in topic 20.[3]) For any of the symptoms you have, or have had in the past, write down your answers to the series of questions we've listed. At the end of the exercise there are additional spaces for you to write about other symptoms or feelings that are not listed here.

Dissociation—feeling as though you are out of your body, watching what is happening to you from a distance. For example, when Ann's counselor mentioned troubling times in Ann's childhood, Ann would protect herself by feeling disconnected from her body. She found she could relieve this symptom by telling the counselor she wanted to change the subject and discuss something pleasant that was happening in her life now, like the course she is taking or an outing with a good friend.

I currently have, or have in the past had, this symptom.

_____ Yes

_____ No

Why is this feeling hard for you?

_____

_____

_____

Where do you think it may have come from?

_____

[3] This refers to a chapter in the Copeland and Harris book Healing the Trauma of Abuse: A Woman's Workbook.

How have you tried to help yourself feel better when you experience this symptoms?

How effective has it been?

Excessive anxiety—Worry accompanied by feelings of nervousness or jitteriness and sometimes shortness of breath, weakness in the arms and legs, and profuse sweating. For example, Nancy experienced anxiety every time she went to visit her parents because she anticipated that an uncle would stop by who had been abusive to her when she was a child. To relieve this anxiety, Ann asked her parents to tell the uncle in advance of her visit that he was not welcome. She learned deep breathing and relaxation and stress-reduction exercises that she practiced regularly. In addition, she cut down on the amount of caffeine she was using.

I currently have, or have had in the past, this symptom.

_____ Yes

_____ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Disturbed sleep—having a hard time falling asleep, waking often during the night, or waking very early and being unable to get back to sleep. This may be the result of recurring nightmares, even though a woman sometimes can't remember them when she wakes. Mary Ellen has addressed this problem by doing relaxation exercises several times during the day, doing journal writing before going to bed, and taking herbal supplements recommended by a health care professional.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Losing track of time—you can't account for where you were and what you were doing at certain times. For example, Marcy kept finding clothes in her closet that she couldn't remember buying. Sometimes people came up to her on the street, actingas if they knew her well, and she had no recollection of who they were. She is dealing with this in three ways: through counseling with a therapist who has experience treating people who have been abused, by practicing being in the moment (discussed in topic 7[4]), and by involving herself in grounding activities such as cooking and cleaning when she is feeling stressed.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

[4] This refers to a chapter in the Copeland and Harris book Healing the Trauma of Abuse: A Woman's Workbook.

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Fear of leaving the safety and security of your living space—In extreme cases, you might be unable to go outdoors at all. For example, Robin only felt safe in the house because of traumatic events that had happened when she left the security of her home. She worked on relieving this problem by leaving the house for short periods of time and going only to safe places, often accompanied by a supporter. She very gradually increased the length of time she could be away and the number of places she could go, and eventually began spending more time away from home on her own.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Hypervigilance—Feeling as though you are always on edge, expecting something bad to happen, always expecting the worst, and feeling tense all over in anticipation. For example, Pasty grimaced every time someone touched her because she expected the touch to be abusive. Patsy explained the problem to several friends and worked with them, practicing being touched without grimacing until she was able to enjoy friendly touch. Whenever this issue comes up she reminds herself that she is no longer in the abusive situation that she believes was responsible for this symptom.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Uncontrollable rage—Yelling, screaming, or hollering at someone, something, or nothing. For example, Jan would have screaming fits toward her husband. Sometimes these fits were unprovoked, and other times they began as the result of a minor incident or misunderstanding. She felt this rage was left over from the physical and emotional abuse she experienced as a child. She learned to deal with this symptom by noticing early warning signs that she was getting stressed; sometimes she was able to recognize a certain circumstance that was likely to lead to an outburst. She would then stop what she was doing, go to a quiet place she had designated in the house, listen to quiet music, and do a relaxation exercise.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Flashbacks—When you experience a vision of past traumatic event along with strong feelings relating to the trauma. For example, while she was involved in some enjoyable activity, Diane would suddenly see in her mind a frightening incident of abuse with her ex-husband. This seemed to drain away all her energy and fill her with fear. Diane learned to deal with this symptom by immediately reminding herself that flashbacks are "old news" that have noting to do with her present circumstance. She would then take a few deep breaths before resuming her other activities.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Hallucinations—Seeing, hearing, feeling, and thinking things that are not based in reality. For example, Marlene had times when her whole life felt out of control. Nothing seemed real. All of her senses seemed to be distorted. She would tell others about things she had seen and heard that made her upset and they knew these things had not really happened. Marlene learned to watch for possible triggering events and early signs of hallucinations. When they occurred, she took time off from work and spent one or several very quiet days at home, doing relaxation exercises, journaling, and engaging in activities she enjoys.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Low self-esteem—Feeling as though you have little or no value as a person. For example, Jodie kept trying and trying to do things that would make her feel good about herself. She got a doctorate as well as a master's degree, had a successful career, and she still couldn't feel like she had any value. She felt this way because she was told over and over as a child that she was "no good for anything." Jodie worked on raising her self-esteem by repeating over and over the affirmation, "I am a wonderful person with lots of talents to share with others." In addition, she started avoiding people who gave her negative feedback about herself, spending more time with people who were positive and affirming.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Inability to trust—Being unable to connect closely and bond with others because of fears of rejection or abuse. For example, Jane often felt lonely and separated from others. However, whenever people attempted to establish a connection with her she would become fearful, avoiding the person and not responding to their invitations. She felt she was unable to trust others because when she was a child her parents had physically and emotionally abused her and neglected her basic needs. To address this issue in her life, she interviewed several counselors until she found one with whom she felt comfortable. They worked together to develop a trusting relationship. The counselor then introduced Jan to a support group of other women who had been abused. In this group she learned to share personal information with others who had similar experiences and who respected her confidentiality. She developed close friendships with several of the women in the

group, getting together with them for walks and movies. With these successful trusting relationships, she began to take more risks, becoming friendly with people at work and at her church.

I currently have, or have had in the past, this symptom

_____ Yes

_____ No

Why is this feeling hard for you?

_____

_____

_____

Where do you think it may have come from?

_____

_____

_____

How have you tried to help yourself feel better when you experience this symptom?

_____

_____

_____

How effective has it been?

_____

_____

_____

Use the following spaces to address other symptoms and feelings you experience as a result of abuse.

Feeling or symptom:

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Feeling or symptom:

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Feeling or symptom:

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Your List of Tools

As you review the responses to your symptoms above, you will discover that you developed some successful tools for relieving symptoms and feelings associated with abuse. What are they?

You will find other ways to relieve symptoms in topics 6, 7, and 13[5]. Review the work you did in those topics and make a list of the tools you have started to use or plan to try.

_____

_____

_____

_____

_____

You may want to make a copy of this list of tools to hang on your bulletin board or refrigerator for easy reference. Use them whenever you have emotional or psychological symptoms or feelings that are uncomfortable or distressing. The more you practice these skills, the easier they will be to use. After a while you will notice that you are using them almost automatically. Your symptoms will become less of an issue in your life and you will feel better and enjoy your life more. This change happens gradually over time.

Ending Ritual

Describe something you are looking forward to that is happening soon.

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_____

Describe something you are looking forward to that will happen in the more distant future.

_____

_____

Optional Activities

1. Spend at least one hour each day doing something you really enjoy. Note how you feel before and after this activity.
2. The next time a symptom or a bad feeling occurs, stop, write the name of the symptom or feeling on a piece of paper, and put the paper in a safe place. As

[5] These refer to chapters in the Copeland and Harris book Healing the Trauma of Abuse: A Woman's Workbook.

you are doing this, tell yourself, "I can control this feeling. I don't need to experience this right now if I don't want to."

Things to Remember Every Day

- I'm not crazy. The symptoms and feelings I experience are normal responses to trauma and abuse.
- I recognize symptoms of trauma and abuse. I relieve them by using the tools I have discovered on my own and through this work.

TAKING BACK CONTROL OF YOUR LIFE*

In my studies I have found that many people who experience psychiatric symptoms or have had traumatic things happen to them feel that they have no power or control over their own lives. Control of your life may have been taken over when your symptoms were severe and you were in a very vulnerable position. Family members, friends and health care professionals may have made decisions and taken action in your behalf because your symptoms were so intrusive you couldn't make decisions for yourself, they thought you wouldn't make good decisions or they didn't like the decisions you made. Even when you are doing much better, others may continue making decisions in your behalf. Often, the decisions that are made for you and the resulting action are not those you would have chosen.

Taking back control of your life by making your own decisions and your own choices is essential to recovery. It will help you to feel better about yourself and may even help you to relieve some of the symptoms that have been troubling to you.

There are several things you can do to begin this process. You can do these things in whatever ways feel right to you. You may want to use a journal to list or write your thoughts and ideas as a way to stay focused on what it is you want, to motivate yourself and to record your progress.

1. Think about what you really want your life to be like. Do you want to:
   - Go back to school and study something of special interest to you?
   - Enhance your talents in some way?
   - Travel?
   - To do a certain kind of work?
   - Have a different home space or to own your home?
   - Move to the country or the city?
   - Have an intimate partner?
   - Have children?
   - Work with an alternative health care provider on wellness strategies?
   - Make your own decisions about treatment?
   - Stop putting up with disabling side effects?
   - Become more physically active?
   - Lose or gain weight?

You can probably think of many more ideas. Write them all down. You may want to keep them in a journal.

2. List those things that have kept you from doing the things you wanted to do in the past. Perhaps it has been lack of money or education. Maybe your symptoms have been too severe. Maybe your treatment makes you lethargic and "spacey". Maybe someone in your life insists on making decisions for you.

Then write down ways you could work on resolving each of the problems that keep you from doing the things you want to do and being the kind of person you want to be. As you do this, remind yourself that you are a intelligent person. You may have been told that you are not intelligent because you have a "mental illness". Experiencing psychiatric symptoms does not mean that your intelligence is limited in any way. You have the ability to find ways to resolve these problems slowly or quickly. You can take small steps or big steps—whatever feels right and is possible for you. But you must do it if you want to take back control of your life.

In the process of taking control of your own life, you may need to change the nature of your relationship with some of the people in your life. For instance, instead of your doctor telling you what to do, you and your doctor would talk about your options and you would choose the ones that felt best to you. You may need to tell a parent or spouse that you will make your own decisions about where you will live, what you will do and whom you will associate with. You may have to tell a sibling who has been overprotective that you can take care of yourself now.

3. Know your rights and insist that others respect these rights. If your rights are not respected, contact your state agency of protection and advocacy (every state has one—you can find it under state listings in your phone book or by calling the office of the governor).

   Your rights include the following:

   - I have the right to ask for what I want.
   - I have the right to say no to requests or demands I can't meet.
   - I have the right to change my mind.
   - I have the right to make mistakes and not have to be perfect.
   - I have the right to follow my own values and standards.
   - I have the right to express all of my feelings, either positive or negative.
   - I have the right to say no to anything when I feel I am not ready, if is unsafe, or it violates my values.
   - I have the right to determine my own priorities.
   - I have the right not to be responsible for others' behavior, actions, feelings or problems.

- I have the right to expect honesty from others.
- I have the right to be angry.
- I have the right to be uniquely myself.
- I have the right to feel scared and say, "I'm afraid."
- I have the right to say, "I don't know."
- I have the right not to give excuses or reasons for my behavior.
- I have the right to make decisions based on my feelings.
- I have the right to my own needs for personal space and time.
- I have the right to be playful and frivolous.
- I have the right to be healthy.
- I have the right to be in a non-abusive environment.
- I have the right to make friends and be comfortable around people.
- I have the right to change and grow.
- I have the right to have my needs and wants respected by others.
- I have the right to be treated with dignity and respect.
- I have the right to be happy.

These rights have been adapted from *The Anxiety and Phobia Workbook* by Eugene Borne (Oakland, CA: New Harbinger Publications, 1995).

4. Educate yourself so that you have all the information you need to make good decisions and to take back control or your life. Study resource books. Check out the Internet. Ask people whom you trust. Make your own decisions about what feels right to you and what doesn't.

5. Plan your strategies for making your life the way you want it to be. Figure out the best way for you to get what it is that you want or to be the way you want to be. Then start working at it. Keep at it with courage and persistence until you have reached your goal and made a dream come true.

A Possible First Step

One timely way you could choose to begin the process of taking back control of your life is to get involved in the upcoming election. You could begin by thinking about and listing the political issues that are most important to you. They may include things like mental and physical health care, the cost of medications, disability benefits, housing, human services, social justice, the environment, education and employment. Jot down some notes about action

you would like to see your community, state or the federal government take in regard to these issues. Then study the candidates. Find out which candidates most closely support your view on these issues and will best be able to create favorable change. Then register before November so you can VOTE for that person or those people.

In addition, if you feel ready, you could become further involved if you choose to by:

- Contacting groups that are concerned with the issues that you care about—ask them for information, volunteer to assist them in their efforts.
- Talking to family members, friends, neighbors and co-workers about your views and the candidates you support - - encouraging them to vote for the candidates you prefer.
- Letting others know about your preferences through bumper stickers, campaign buttons and lawn signs.
- Writing a letter to the editor of your newspaper to share your views or calling in on radio talk shows.
- Volunteering to work at the polls, or to work for a particular candidate.

Whether your candidates win or lose, you will know you did the best you could and that through your efforts more people are now informed about the issues. You may even decide that you want to run for office.

BUILDING SELF ESTEEM*

In my work I sometimes feel that there is an epidemic of low self-esteem. Even people who seem to be very sure of themselves will admit to having low self esteem that often makes them unhappy, keeping them from doing some of the things they want to do and being the kind of person they want to be. In fact they may say that low self-esteem causes, or worsens, their bouts of depression and anxiety. I know it has been a big factor in my life. I feel that I have always been working on raising my self-esteem and that I will always need to do that. There is no one-way to raise self-esteem. There are many different things you can do to work on this. I find that I am always looking for good ways to raise self-esteem. This article will describe several ways you can raise your self-esteem.

Get Involved

Right now you have an opportunity to do something that will help you to raise your self-esteem. Once every four years, you can vote for the person you would like to be the next president of the United States. You also have the opportunity to vote for other national, state and local officials. Irrespective of the outcome of the election, informing yourself about the candidates and voting for the ones who support issues that are important to you can make you feel good about yourself, raising your self-esteem. Begin the process by thinking about the issues that are important to you—education, health care, the environment, taxes, defense spending, etc. If you don't know how you feel about these issues, read some related articles and talk with people who have the information you need. Then, when you know how you feel, find out which candidates support your views. Then vote for those candidates. If you feel strongly about certain candidates, and have the time, you may want to volunteer to help them with their campaign. Activism will give your self-esteem another boost.

Take Good Care of Yourself

Another way you can build your self-esteem is to take very good care of yourself. You may take very good care of others and put your own personal care last. Or your life may be so busy that you don't take the time to do things you need to do to stay healthy. You may feel so badly about yourself that you don't bother to take good care of yourself. Some of the things you can do to take good care of yourself include:

- Eating three meals a day that are focused on healthy foods—fresh fruit and vegetables, as well as whole grain foods and rich sources of protein like chicken and fish
- Avoiding eating food that contains large amounts of sugar, caffeine and food additives—if you can't pronounce the ingredients, you may want to avoid it
- Getting outside and exercising every day
- Spending some time each day doing something you really enjoy
- Spending time each day with people who make you feel good about yourself
- Having regular check-ups with your health care providers

Change Negative Thoughts about Yourself to Positive Ones

Work on changing negative thoughts about yourself to positive ones. You may give yourself lots of negative self-talk. Many people do. This negative self-talk worsens your low self-esteem. You can decide now not to do this to yourself. That's great if you can do it. However, negative self-talk is often a habit that is hard to break. You may need to work on it more directly by changing these negative statements about yourself to positive ones. Begin this process by making a list of the negative statements you often say to yourself. Some of the most common ones are:

- Nobody likes me.
- I am ugly.
- I never do anything right.
- I am a failure.
- I am dumb.
- Everyone is better than I am.
- I'm not worth anything.
- I've never accomplished anything worthwhile.

Then develop a positive statement that refutes the negative one. For instance, instead of saying to yourself, "Nobody likes me" you could say, "Many people like me". You could even make a list of the people who like you. Instead or saying, "I never do anything right" you could say "I have done many things right." You could even make a list of things you have done right. It helps to do this work in a special notebook or journal.

When you developed positive statements that refute your negative statements, read them over and over to yourself. Read them before you go to bed at night and when you first get up in the morning. Read them aloud to your partner, a close friend or your counselor. Make signs that say a positive statement about you and post them where you will see them—like on the mirror in your bathroom. Then read them aloud

every time you see them. You can think of some other ways to reinforce these positive statements about yourself.

Get Something Done

Low self-esteem is often accompanied by lack of motivation. It may feel very hard to do anything. It will help you feel better about yourself if you do something even if it is a very small thing. You may want to keep a list of possibilities on hand for those times when you can't think of anything to do. Things like cleaning out one drawer, washing out the inside of your refrigerator, putting a few pictures in a photo album, reading an article you have been wanting to read, taking a picture of a beautiful flower or a person you love, making a bed, doing a load of laundry, cooking yourself something healthy, sending someone a card, hanging a picture or taking a short walk,

Make a list of your accomplishments. You may not give yourself credit for all you have achieved in your life. Making a list of your accomplishments will help you become more aware of these accomplishments. It will also help change the focus of your self-thoughts to positive ones. You can do this exercise again and again, whenever you notice your self-esteem is low. Get a big sheet of paper and a pen you feel comfortable with. Set the timer for twenty minutes (or as long as you'd like). Spend the time writing your accomplishments. You could never have a paper long enough or enough time to write them all. Nothing is too big or too small to go on this list. This list can include things like:

- Learning to talk, walk, read, skip, etc.
- Planting some seeds or caring for houseplants
- Raising a child
- Making and keeping good friends
- Dealing with a major illness or disability
- Buying your groceries
- Driving your car or catching the subway
- Smiling at a person who looks sad
- Taking a difficult course
- Getting a job
- Doing the dishes
- Making the bed

Do Something Special for Someone Else

Have you ever noticed the good feeling that washes over you when you do something nice for someone else? If so, take advantage of that good feeling that

comes from helping someone else by often doing things that are "nice" or helpful to others to build your self esteem. Watch for opportunities that come up every day. Buy your partner some flowers or even one rose. Send a friend a greeting card. If someone you know is having a hard time, send them a note or give them a call. Go out of your way to congratulate people you know on their achievements. Visit a patient at a nursing home, in a hospital or a "shut-in". Play with a child—read them a book, take them for a walk, push them on the swing. Do a chore for someone that might be hard for him or her, like raking the leaves or mowing the grass. You may even want to volunteer for an organization that is helping.

Other Quick Things You Can Do to Raise Your Self Esteem

Following is a list of other things you can do to raise your self-esteem. Some of them will be the right thing at one time, while another thing will work another time. There may be some you choose not to do—ever. You may want to post this list on your refrigerator or in some other convenient place as a reminder.

- Surround yourself with people who are positive, affirming and loving
- Wear something that makes you feel good
- Look through old pictures, scrapbooks and photo albums
- Make a collage of your life
- Spend ten minutes writing down everything good you can think of about yourself
- Do something that makes you laugh
- Pretend you are your own best friend
- Repeat positive statements over and over again
- You can add more ideas to this list as you discover them for yourself.

In Conclusion

Work on raising your self-esteem may go on for the rest of your life. However, this is not a burden. The kinds of things you do to raise your self-esteem will not only help you to feel better about yourself, but will improve the quality of your life while energizing and enriching it.

COLLECTIONS*

I collect instances.

I used to collect pigs, cast-iron soldiers. In 1976, I collected all sorts of bicentennial paraphernalia. I wasn't much of a patriot, but is seemed such a milestone in what we call a "nation".

Instances, however, collect my sanity, as I collect instances. Every individual has collected some odd, or not-so-odd, item or another. Instances, however, are every individual's most vital collection in their lifetime. And often the most overlooked.

I would wager most of us neglect instances. Of course, we collect stories. Perhaps less so in this fast-paced age of the internet and the printed word. But we gather stories in some form: family tales, office anecdotes, high school remembrances. Stories make up our lives—collages of memories. More intricate, however, are individual recollections. Now I collect instances in defiance of my long-held beliefs of my self as a loser. A fake. An inept human being.

I grew up basically not fitting in. None of us fit in. Some of us fit in better than other, but the squeeze is harder for some than others. I was a tight squeeze, faced daily with quirks, let-downs and embarrassments.

Disappointments. Failures. Never quite fitting in. A lot of pain. Years of belief that I was a failure, incapable, defective, bad... I have notebooks to attest to this, condemning myself, years of eating disorders to try to destroy myself, tirades upon tirades with myself, with friends, who only remember wishing somehow I could not be so tremendously hard on myself. I could not see otherwise—I was just not good enough. There were not enough instances of goodness in my collection.

Like collecting baseball cards, I didn't opt for the choice cards. Sooner or later, this led to deep isolation. I had no idea how I would get out. I had to start from square one.

I started to look at myself in others' eyes, in particular, in the eyes of one friend I pretty well believed loved me.

I pretty well believed she liked me a lot. This was a leap of faith.

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* Karen Milstein, Wisconsin Consumer (December 2001). Bureau of Community Mental Health, WI Department of Health and Family Services, *Recovery and the Mental Health Consumer Movement in Wisconsin.* Used with permission of the author. Please contact the author through Yahara House for permission to reprint, 608-280-4700.

I watch how she watched me. I watched how maybe she looked to me for confidence, for support. I watched how maybe she needed me. As we all need each other. I looked for instances. Then I looked slightly further abroad. To further instances in my life. People, strangers, smiled at me. At me! When I gave them a chance—an instance—they even sometimes spoke to me. If I gave people space, they sometimes took it. Like slack—it is taken up.

I collect instances. I started taking the more valuable cards. Remembering. Noticing. Collecting them and keeping them for myself.

> Instances also come in the form of events. I made instances out of tasks. My first major task-oriented instance to get me out of isolation was to take on the major task of editing a local feminist newspaper (that is, by the way, no longer in print). I co-edited an edition on women and mental health. It was easier than it sounds: there was a beginning, a middle and an end. I started a task, worked hard and finished. This is a perfect instance to work on, because I knew if I worked on it, I would finish it and have achieved an instance. A fine addition to my collection.

The collection can never be too big. You can trade old cards for new ones. Pack some of the old instances away in the closet and gather new instances in the closet for an ever stronger ego collection.

Tasks. Glances. Achievements. Every piece of successful writing. Instances.

Attention! This collection is not to go to your head! This collection of instances is to give you a gentle pat on the back, a rub on the stomach, warmth in the heart. To fire you up to fire others up. To keep you going to keep others going. To light your eyes to shine in others' eyes.

We fill each others' collections of instances for where else would instances come from?

10 WAYS TO DE-STRESS YOUR LIFE*

1. Live simply. Don't clutter up your life with too many things.
2. Take care of yourself. Get enough sleep; eat healthy foods.
3. Think positively. Fill your mind with uplifting images.
4. Be cooperative. Resist the common tendency to want things your own way all the time. Try to see another point of view.
5. Get involved in a good cause. Feel like you are making a difference in the world, even if it's in a small way.
6. Live one day at a time. Make the most of the moment. Yesterday is gone, and today will be, soon enough.
7. Exercise. Do something you really enjoy. Restore yourself.
8. Maintain balance. Devote time to all aspects of your life: spiritual, emotional, family, career, community, physical, mental, material.
9. Give yourself credit where credit is due.
10. Realize you can't do everything.

SAFETY PLANNING*

A. Numbers to call for help:

1. List names and numbers of friends, relatives, battered person's shelter/agency, hospitals, churches, where you can go for help.
2. Find a safe place to hide the number to the battered shelter/agency, like at a neighbor's, in freezer, plant, tampon box.
3. Post number for battered person's shelter/agency under a fictitious name (first name only) so abuser doesn't know you have it.
4. Keep the police/sheriff's number posted close to the phone.
5. Memorize all important numbers.

B. House and car keys:

1. Number one rule: keep all keys out of sight of the abuser.
2. Have extra keys made. Give extra keys to friends, neighbors, relatives: people who can be trusted.
3. Tape or hide extra keys somewhere safe: desk drawer, wheel well, out of the house if possible.
4. Try to obtain abuser's set of keys to vehicle, especially if he/she does not use the car or if it belongs to you.
5. If the abuser has a set of your home keys, change the locks to your home.

C. To prevent the abuser from immobilizing vehicle:

1. Get a lock for the hood and gas cap.
2. If the hood can only be opened from inside the car, keep the doors locked at all times.
3. Try to be sure that the abuser does not have a set of keys to the car.
4. Try to get your keys before the abuser does—always keep your set of keys hidden from abuser.
5. Keep your car parked in places where the abuser will not look for it.
6. If you need glasses to drive, have an extra pair in the car in case the abuser takes/destroys the pair you wear.

D. To prevent the abuser from entering your home:

1. Get locks on doors and windows. Get double keyed deadbolts for doors.

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* Domestic Abuse Intervention Services (Fall 2001). *Volunteer Training Manual.* Please contact for permission to reprint, 608-251-1237.

2. Keep keys out of sight of abuser. If abuser has set of keys, change locks.
3. Reinforce/repair windows and doors.
4. Obtain alarm or dog.
5. Move to another residence.
6. Get peephole installed.
7. Keep doors and windows locked at all times.
8. Never let abuser into your residence.
9. Install outdoor lights.

E. Inform neighbors, friends, and relatives of the abuse:

1. Give friends, neighbors, and/or relatives permission to call the police.
2. Set up signals asking for help of indicating danger with these people such as:
    a. Flicking on and off the lights.
    b. Set up a password/sentence which indicates something isn't normal.
    c. A curtain in a certain window is open or shut.
    d. A plant that usually hangs in a certain window isn't anymore.
    e. SCREAM! (scream "fire")
    f. Knocking on the wall
3. Don't give information to untrustworthy people or people that like or trust abuser.
4. Get the OK with friends, neighbors, etc. to come to them in the middle of the night.
5. Teach your children how to call the police. If possible, develop a signal with them.

F. Telephone

1. Get one if you don't have one.
2. Change your number and make it unpublished.
3. Refuse to argue with abuser on the telephone.
4. It is legal to tape your own phone conversations: you can tape calls from abuser to document abuse.
5. Keep all important/emergency numbers near the phone.
6. Hide a phone in your home to prevent abuser from disconnecting it.

G. Money:

1. Open a personal account separate from the abuser's.
2. Put aside some money for emergencies. When purchasing groceries or other items, write the check for over amount and put money in your personal account. Borrow money from relatives, banks, and hide it or put it in you bank account.
3. Hide money where it is easily accessible to you.
4. Sell rings, silver, antiques, and other items of value so you have ready cash.
5. Get travelers checks and keep them hidden.

H. Personal Items:

1. Keep personal items prepared in case you must leave in a hurry. These could include: clothing, medication, baby needs, car seat, cash, personal hygiene products, valuables, addresses/phone numbers, glasses, important papers (driver's license, birth certificates, etc.)
2. Keep items with friends, neighbors, or relatives.
3. Hide important items somewhere (under spare tire, wrapped in freezer, or rent a locker at the YMCA, airport or train station.)

I. Important papers and documents:

1. Keep important papers and documents prepared in case you must leave in a hurry. These could include: birth certificate, marriage license, divorce decree, social security card, insurance policies, bank papers, stock accounts, bank mortgages, care title, paycheck stubs, driver's license, etc.
2. When possible, keep important papers in safety deposit box at bank.
3. Always have easy access to originals or copies.
4. Hide papers with friends or relatives.
5. Wrap and hide in freezer, plants, etc.
6. Always carry your restraining order with you.

J. Children:

1. Even small children are affected by violence: explain it to them.
2. Inform babysitter, schools, medical facilities, parents of your child's' friends, etc. that the child should not leave with the abuser.
3. Develop a safety plan with children to use when they are scared or when you give them a signal (where to hide, when to leave, how to call the police).

K. If there are weapons in the house belonging to the abuser:

1. Hide or throw away all ammunition.
2. Hide weapons or lock them away in the trunk of a car to which the abuser doesn't have keys.
3. Put knives in inaccessible places.
4. If law enforcement is called, ask them to take away the weapons.

L. Hiding places

1. Be aware of your surroundings.
2. Know good places in your house to hide (close to windows or doors for easy escape if necessary.)
3. Make an escape plan from each room. Get rope ladders hidden in upper story rooms for escape.
4. Make a "safe" room in your house which has a lock on the door, a phone, and from which you can escape the house.
5. Do not lock yourself into a small space such as a car (windows can be broken) or into a room with only one exit.
6. Be aware of your physical capabilities—can you outrun your abuser?
7. Hide underneath a car, in a ravine, shed, etc.
8. Lock yourself in a stranger's car rather than your own if you don't have the keys to drive away.
9. Don't count on a stranger's help.
10. Know in advance where you will go if you need to leave your house.

M. How to protect yourself when being attacked:

1. Be aware of the abuser's cues (physical behaviors, circumstances) before assault. Try to leave before the assault.
2. Know ahead of time what you are capable of doing to defend yourself, such as gauging eyes, kick to knee or crotch, run, etc.
3. Never pick up a weapon unless you are sure you will use it. (The danger is that when you become afraid to use it, the abuser might take it and use it against you.)
4. Black pepper, chili powder, salt or hairspray in the eyes of the attacker can be effective.
5. If all else fails, roll up in a ball and protect your head.
6. Find a self-defense class in your area. Check it out. If it feels safe and fulfills your needs, take it.

SOMEONE WHO BELIEVED IN THEM HELPED THEM TO RECOVER*

People who have significantly recovered from mental illness frequently say they were greatly helped by someone who believed in them. One woman stated that there was a doctor who..."believed in me. She never gave up. She was the only one who didn't give up as far as [my] being in the hospital." Another woman stated that for her it was a caring therapist. She said, "He was the first person I encountered out of the ordeal that actually had some sort of feeling. He was sympathetic at least and was understanding. He was really helping me out and motivating. Motivating me to keep on fighting, don't give up...Don't let them get their way, just keep on fighting."

> A nurse working with me reflected that the most important elements to her recovery were, "Having a mentor, a connection and a relationship...someone I made a strong connection to and they made one to me and they believed in me and I knew it...There was a knowing in their eyes that I saw that said I see you and I really believe in you. Someone that carried me. Somehow that encouraged me to not fall backwards."

Another woman in describing the residential counselor as the most important person in her recovery stated, "She believed in me...She sent me a card that said, 'keep up the good work.' She saw a spark in me. She told me from the start I had a good deal going for me. She helped encourage me and put courage in me. She gave me incentive."

The people who work in residential services are often the ones whose belief made a difference in someone's recovery. Jim is an example of such a worker. For 8 years he has patiently and respectably offered his heart and hand to consumer/survivors. Recently he described a priceless moment with a consumer/survivor, Eric, that everyone else had written off. During a walk with Eric, Jim commented on the beauty of the sky, Eric replied, "It is of no importance to me now; why are you telling me about it."

Jim was delighted. It was one of the first times that Eric had expressed a strong emotion directly to another person. It was also one of the first times that he stated that his needs were different from those of others. Jim thinks that Eric now feels safe enough to express strong feeling within their relationship. Over several years, Jim has carefully won Eric's trust through listening to his deepest requests. For instance, Eric has bitterly complained that he has not felt alive on his major tranquilizer. Jim has been able to help Eric to negotiate a much lower dose. Though in the past Eric suffered increased paranoia when his medication was lowered, he has not done so this time. I am sure this is because of his close relationship with Jim which has allowed him to feel safe with greater feelings. Eric has also started to listen to different music. For many years he would only listen to heavy metal which Jim felt

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* Daniel B. Fisher, M.D., Ph.D. © 1999. National Empowerment Center, Inc. All rights reserved. Available at: http://www.power2u.org/recovery/someone_who.html.

he needed to listen to because it was needed to drown out his painful thoughts. Now Eric is able to listen to soft rock and folk.

When I asked other staff about Jim they said he reminds them of Yoda, the wise being from "Star Wars." When he walks into a room everyone feels a sense of calm and peace, yet he can be firm. A consumer called and was abusive to him on the phone. He calmly said, "I won't talk with you when you treat me that way. When you can have a civil conversation call me back." In a few minutes she did and they had a productive conversation. He has a sense of humor. One day a consumer was getting very angry on the bus. Others felt threatened, but Jim suddenly burst out laughing and so did the consumer. When I asked Jim what he felt was most important in his relating with consumer/survivors, he said, "I just accept them, the real person. Then they will present more and more of themselves to you." Such an elusively simple description of the beauty he weaves.

> Jim's manner reminds me deeply of the contact I yearned for and occasionally found in my own journey to recover my own lost self. After a year with an emotionally remote analyst, I sought a different kind of therapist, one that was more human and showed more of himself to me. I made one request at the start of our therapy. "Could you please be a real person with me?" He said he would try to and the combination of his acceptance of my request and his humility planted the roots of trust. There were many tests of our relationship, but he was consistent in his support of me at a deep level. When I told him I wanted to become a psychiatrist he said he would be there for my graduation and he was, even though I was no longer in therapy with him. When I would thank him for an insight he would insist that I had done the work and the healing. He said he had merely provided the setting. When I asked how he felt about my attending a group with another therapist. He said he trusted that I knew what I needed to heal.

Equally compelling is the centering and spiritual renewal coming for the person who does the believing in another. Whether it is for our children, lover, pet or person in need of help, there is deep meaning for the person who can step outside their world to support another's. A client I had seen through many hospitalizations recently had a long period free of such episodes. She clearly had a new light in her eye. When I asked what had changed she said now that she was working as a provider she had a sense of meaning and purpose in her life. Helping others gave her sufficient meaning that she felt her life was worth living.

These observations recall the research of Carl Rogers into the nature of the helping relationships. He stated that "the safety of being liked and prized as a person seems a highly important element in a helping relationship." (On Becoming a Person, 1961). Martin Buber also describes the importance of having someone believe in you. He calls this characteristic "confirming the other... Confirming means accepting the whole potentiality of the other. I can recognize in him the person he has been created to become." Rogers goes on to state that "if I accept the other person as something fixed, already diagnosed and classified... then I am doing my part to confirm this

limited hypothesis. If I accept him as a process of becoming, then I am doing what I can to confirm or make real his potential."

These descriptions, however, were mostly for people with moderate emotional problems. When someone is labeled with mental illness, it is as if all that has been learned to be helpful in therapy is thrown out. Medical students are taught to medicate not to converse with mental patients. They are told that people labeled with mental illness have a brain disease and you cannot talk to a disease. Our lived experiences speak otherwise. Our lives show that people labeled with mental illness need a therapist and other people who believe in them.

We who have been labeled with mental illness, remain just as human if not more so than others who are temporarily not labeled. Our needs are human needs of which the most basic is to enter into trusting, loving, and caring relationships. These relationships need to be nurtured and cultivated for us to find the compass of our true self to guide our recovery. Any system of care which disturbs or interferes with these relationship is preventing not promoting recovery.

THE IMPORTANCE OF HOPE*

I could go back and gripe about my past. It was the standard horror story about the tiniest of little girls suffering incomprehensible sexual, physical, and emotional abuse. It was the story of the teenager who ran away to live on the streets and numb her pain with drugs. It was the story of the woman who married a man just like her father only to see the cycle of abuse continue. And throughout it all, the story of horrible voices and terrible thoughts hurtling me toward self-destruction.

I could write about all that, but what's the point? I can't go back and change a damn thing about it. The best I can do is use it as a learning experience. So this story isn't about all that old stuff. This is about living. This is not about undoing past wrongs, but building a strong, independent woman from them. I have been reborn as a fresh, whole human being!

So how did this rebirth happen? It was purely by accident, and probably because I was ready at last. My life had crashed again. I had just moved back to Wisconsin from Hawaii—a single mother with no income. I was almost totally non-verbal and very poorly functioning; I was just barely existing. The school year was ending and I received a message from the school counselor that I really must get my son into therapy; his behavior was just too much for the teachers to handle. Matt had already seen every kind of counselor, psychiatrist, psychologist, and social worker in his six years and none of them had made an ounce of difference. I put the note aside and went on with my non-life. But as summer passed I began to think I'd better show the school that I was at least trying, so I picked a name out of the phone book and set up an appointment. For the first three sessions, half of the time was spent with Matt alone, and the other half was spent with the two of us together. At the end of that third session the therapist pulled me aside and told me that he thought he would be able to help Matt, but to really be effective I would need to get therapy myself.

I was astounded. Of all the times Matt had been counseled, never once had anyone suggested that I should get help! Of course I was mad. But then I thought about all the times that I'd been hospitalized and given various psychiatric diagnoses. I'd always rejected the thought that there was something wrong with me, so I'd never followed through with the meds or other recommendations. This would be my chance to prove all those doctors and this psychiatrist wrong! I agreed to start my own therapy.

That in itself was an eight-year journey. I had gotten lucky and chosen a very patient and empowering therapist. For the first six months I said almost

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* Judie Robson, Wisconsin Consumer (December 2001). Bureau of Community Mental Health, WI Department of Health and Family Services, *Recovery and the Mental Health Consumer Movement in Wisconsin.* Used with permission of the author. Please contact the author for permission to reprint, 920-236-1276.

That in itself was an eight-year journey. I had gotten lucky and chosen a very patient and empowering therapist. For the first six months I said almost nothing—just the "name, rank and serial number" type of information. But then one day the therapist was offhandedly disclosed something about a mean name his father called him when he was young. The dam broke and I started weeping. I hadn't cried once since I was about six years old; I didn't think I could cry (or laugh) anymore. That was the turning point. Slowly but surely I started trusting and revealing the tangled mass that was my past. I started taking tiny, uncertain steps toward recovery. Each time I said, "I can't," my therapist would gently suggest that I could. He showed faith in my abilities to grow and learn and finally I have a satisfying life. He gave me HOPE. I went from an extremely introverted, isolated, barely-functioning human being to a woman who began asserting herself, taking care of herself, and actively working toward a better future. That hope was intoxicating! It gave me power that I never knew I had. By the time I quit seeing my therapist five years ago, I had earned by second bachelor's degree, been working full-time for three years and was showing signs of frequent happiness.

That's not to say that therapy alone helped me, but it gave me the hope I needed to do other things. I needed medications and started taking them consistently, except for a two-year period when I had no insurance. I also began to build a very small social network and became more active in my community.

> The best thing is that I didn't stop learning and growing when I stopped therapy. That hope was so firmly implanted in me that I've continued on and haven't given up, even when I have a small back-slide. I don't have a perfect life, and I certainly have all the same stressors that everybody else has (whether suffering from a mental illness or not), but I've learned that I can cope with them and move on.

I'm not a hero, or even a great role model. I'm just a person with hope, and I realized that I have the ability not just to survive, but thrive!

RECOVERY IS WORTH THE HARD WORK*

So you come to a point where you want to change things in your life. You are depressed, unhappy, have difficulty in relationships; feel an awful aloneness. This aloneness can be a very painful feeling, akin to a kind of deadness or inner emptiness or a sense of void. Your coping skills are not working. You can feel suicidal, hopeless and helpless. And yet even when one wants to change, the process of change is extremely difficult. It takes tremendous courage to change one's view of the world. We learn our view of the world as children. If parents were there sometimes and other times not, we learn the world is not a consistent kind place. One can be in serious psychological pain and yet to change is like climbing Mount Everest. The patterns we know, though they bring us pain, are what is familiar to us and what we know.

One of the hardest things for me to understand and learn to control is the whole flight or fight response. I know for me and many of my friends the response is such an automated part of one's life that it is hard to see the mind body connection. My boss at work is upset over something and I want to run and hide, the sense of danger is overwhelming. The whole stress response can overtake my life. In a panic attack one can feel like one is dying. In an attempt to get out of this response I am trying several techniques. I am very excited about the Yoga classes and massages at Cornucopia and Yahara House. Nothing is worse than when someone tells you to relax, just relax. One has to learn to relax. Grounding techniques, visual image, etc. and trying to feel safe. It is extremely hard to live with the anxiety; it feels like the body is racing and racing, and each second can be excruciating.

> Another kind of anxiety that can be tremendously debilitating is "separation anxiety". When I was born my mother was very depressed and wanted me to be with her. The whole process of separation and individualization did not occur. A part of her wanted to let go of me, but her own anxiety at being without me and alone was overriding. Kindergarten was the teller of the future to come. I cried hysterically and was told that I was too emotionally disturbed for school. The nun put me in a room by myself because I disturbed the other kids. My mom told me that the teacher was evil and after me. A horrible and terrible year full of depression and nightmares. The whole world was angry with me. My mom would throw me out the door and tell me to go to school sometimes, but most of the time I stayed home. My mom and I were totally intermeshed. In high school we wore some of the same clothes. And then when I was 24 she died and I was out in the world alone. This kind of anxiety makes one feel totally immobilized and unable to function when one is alone. Step by step, and sometimes very painfully, I had to learn to be alone. My mom was so

*Anonymous (2002). Written for the *NPW Consumer Curriculum.* Permission to copy this article has been granted by the author.

scared of losing me that if I just was upset and went to my room, she was scared that I was going to kill myself. She was terrified of being alone without me.

The words that help me understand myself are the holding introject. For the infant and child to gain significant autonomy, two qualities of experience are essential. The first is narcissistic, related to feelings of personal value; the second is "holding and soothing". Good-enough mothering in early life usually provides essential holding and soothing. With time the holding and soothing provided by the parents is internalized, first as holding interjects and then as psychic structure. If however the mothering is not good enough in providing holding and soothing in the phases of separation-individualization, the child cannot hold and soothe herself and must depend on external objects to provide it. An example of holding and soothing oneself is if one has a bad day at work, the kind nurturing parent tape says things like everyone makes mistakes, it is ok to make mistakes, it might be helpful to watch something funny on TV, a hot cup of hot chocolate might feel good. My parent tape from my mom in this situation would be to tell myself it is not ok to make mistakes, I was a terrible bad person and I would feel like cutting to comfort myself. My mother couldn't soothe and comfort herself so she could not give me these skills.

So if one in childhood does not acquire these soothing and comforting skills one must look externally for it; which is to turn to other people. Thus it becomes a problem when sufficient interaction with external holding self objects (other people) is not existent and intense separation anxiety takes place. This then ensues a rage with a forthcoming regression. This separation is an incredibly painful feeling, akin to a kind of deadness or inner emptiness, or a sense of void. One can feel that one simply does not exist. With the regression, the separation anxiety can lead to annihilation anxiety which can causes suicidal feelings. This anxiety is related to the loss of self and psychic structure. Thus under this sway of regression, one tries through fusion and incorporation, to retain the self-object.

In my life this was played out in a dramatic way. When I first got help, I saw a psychiatrist who gave me for the first time in my life, the soothing and holding neither of my parents where able to give me. It felt so good to have someone to lean on, someone to talk to about my feelings, someone that gave to me unlike my parents who I nurtured as a child. However, from the psychosis from my schizoaffective disorder I deteriorated during the 4 years I saw him. I kept failing at every job I did and my self-esteem was eroded. So in my psychosis I attempted a very serious suicide attempt. I was at work and my experiments kept not working out, so I just lost it to the delusion of my evilness and that I had to kill myself. I was in intensive care for three days and do not remember any of that. Consequently, my psychiatrist said that he could not see me anymore and that I should go on disability and be in the public sector where I could get more help than just he could do. With the extraordinary separation anxiety and regression I became totally psychotic. The pain was unreal, just excruciating. I remember my psychosis of wanting to kill my psychiatrist and myself, but I don't remember the actual reality of telling the nurses this. Due to my

threats I then ended up in Mendota. At this point my psychiatrist clearly diagnosed my as having schizoaffective disorder and clearly psychosis. He had also treated my mom the last year of her life and saw the impact of her mental illness on me.

Unfortunately I did not get the help the psychiatrist wanted for me and I just kept getting more and more psychotic. The person that visited me from crisis in Mendota said to me that therapy had fucked me up. I kept calling crisis and they told me not to call anymore. As my current therapist said, that did not mean that my needs went away. In an attempt to fuse back with my psychiatrist I wrote him letters practically every day.

Without any help from the system, I went into my own world of voices and delusions. I lost all contact with the world. People talked to me, but I didn't understand anything they said. I was hospitalized voluntarily 3 times, but I was just seen as borderline and manipulative. The voices told me to get in my car and that they were taking me to a monastery where I would get well. On the road to the monastery the voices told me to trust in God and take my hands off the wheel and I did. I went into a tree and miraculously survived. Fortunately someone saw the accident and called an ambulance. I regained consciousness in the emergency room.

I did not realize that I had an accident. I was hospitalized; but the psychiatrist attributed the accident to borderline acting out and screamed at me, saying that I was a lawyer trying to get money from the accident. This is so ludicrous. As my lawyer friend just told me years later you can't sue a tree. They released from the hospital with no med changes and wanted me to go to the grow program which I thought was on the planet mars. And then my delusion became that I had to have a kidney transplant and go to into a coma and then my old psychiatrist would help make me well. I was trying to fuse back with him so he could give me self soothing. The hospital charged me with trespassing and I ended up in Winnebago for 4 months. When I arrived in Winnebago they told my Dad that I was so psychotic that I would never come back into reality. Fortunately they were wrong.

The good part of this story was that after being released from Winnebago, I went into a group home, got an excellent therapist who specialized in borderline personality disorder and schizophrenia. Also upon leaving the group home I went into a CSP. With the adequate soothing and holding from social workers and my therapist and learning how to incorporate this into my own skills each year, I get better and better. I have psychosis; but with the better medications and help in coping skills, I am learning how to handle it so it does not interrupt my life. I have worked part-time for the last 8 years.

In June 1999 I joined Yahara House which has helped me tremendously. When I come into the building people say HI and it makes me feel so welcomed and part of the community. I feel safe here. It is a place where people appreciate the strength and courage it takes to deal with mental illness. For example, I recently was offered a job interview and came to work support dinner to talk about my anxiety. Again it is

about adding skills to my self- soothing and kind nurturing parent tape. We talked about not obsessing about the interview, that I could just see if I wanted the job and that I could believe in my competency. The more one learns these skills the less anxiety one has and the more competent one feels. It is important that one is not treated like a child and just nurtured and cared about, rather it is about incorporating these skills oneself so one can be an adult in this world and handle the challenges of the adult world. When I look where I was in 1991 when I was in Winnebago to where I am now it is amazing. Recovery is possible and is worth the hard work.

THERAPY FOR POST-TRAUMATIC STRESS AND DISSOCIATIVE CONDITIONS: WHAT TO LOOK FOR AND HOW TO CHOOSE A THERAPIST*

One of the primary roles of Sidran Institute's Information Service is to assist people who have been traumatized in finding various kinds of help. "Treatment" is usually sought when the behavioral adaptations (usually called "symptoms") typical of trauma survivors become disabling, interfering with work, home life, recreation, sleep, parenting and other aspects of daily function.

Our aim is not only to help people feel better and function better, but also to help them learn to be informed and empowered consumers in general and consumers of mental health services, in particular. We hope trauma survivors find that taking appropriate and well-considered action to improve one's life is made a little easier by the information on this page.

If you are currently in crisis: The process of choosing a helpful therapist takes some time, thought, and focus. If you are currently in a crisis, or are worried that you might hurt or kill yourself or someone else, please contact your community's mental health center, hospital emergency room, or crisis hotline. When the crisis has passed, this brochure will help you organize the task of finding a therapist for on-going treatment.

What is Good Trauma Therapy? A Good Trauma Therapist?

Historically, mental health treatment has been treated according to the "medical model": the "sick" patient treated by the powerful doctor, who has the responsibility, the expertise, and the tools cure the illness. The patient's job is to be compliant and to follow orders. With some practitioners, this model continues to this day.

Recently, however, some therapy models recognize that individual distress is often caused or made worse by poor social, political and economic environments as well as by harmful family dynamics. Trauma survivors are generally best served by therapists who work from an environmental framework, or "trauma model", as they are also more likely to see their clients as experts in their own lives, and as partners in healing.

Later we will look at some of the different disciplines, approaches and techniques most appropriate to trauma therapy. Suffice it to say, however, that good trauma therapists come from every discipline, work in all settings, use a variety of approaches and techniques, and have a wide range of credentials and experience.

There are aspects, however, that the best trauma therapists have in common. We will start by discussing what constitutes good trauma therapy, and then explore how to find it.

> As Dr. Bessel van der Kolk of Boston University explains, most trauma survivors benefit from one-on-one psychodynamic therapy. It "allows disclosure of the trauma, the safe expression of related feelings, and the reestablishment of a trusting relationship with at least one person".
>
> Therapists do rest much of their practice on the basis of their professional training. But perhaps as much as anything else, they rest their practice on their integrity and personal talents—on their perceptions, feelings, insights, intuition, and the degree to which they can hear unspeakable truths. "Pay *more* attention to the therapist's intellectual and emotional equipment than theoretical system," Dr. van der Kolk advises survivors. "Pay attention to whether the therapist really wants to hear the troubles you have to tell. Ask yourself, 'Do I feel validated? Is the therapist really listening to my story?'"
>
> If validation is one important selection criterion, Dr. Judith Herman, Director of Training at the Victims of Violence Program at Cambridge Hospital in Cambridge, Massachusetts, makes clear a second criterion and one that seems of equal importance: An effective trauma therapist empowers the survivor rather than imposes a cure.
>
> The dual formulation of validation and empowerment seems to be fundamental to post-traumatic therapy.
>
> *Excerpt from* Unspeakable Truths and Happy Endings: Human Cruelty and the New Trauma Therapy, *by Rebecca Coffey, Sidran Press, 1998, pp. 85-86.*

The idea of the therapist and client working together as partners, sharing responsibility and expertise is still radical in many mental health settings. But for trauma survivors, this is in many ways the key to success in therapy.

> When treater and client share the trauma perspective they can collaborate. A shared perspective allows collaboration between the individual, who has expertise on him or herself (the client), and the individual who has expertise on the process of healing (the helper). Helper and client collaborate to identify the central concerns of the

survivor. They work together to improve the survivor's life. Treatment requires both people's active participation. The trauma model is also an empowerment model. The helper has useful information to impart, but is not "the expert" or "the authority" on all matters concerning the survivor. The client is an important member of his or her own treatment team, and everyone on the team needs to collaborate to help the client move forward.

The four most important things a therapist has to offer a survivor are as follows:

- Respect
- Information
- Connection
- Hope

With these four components, any relationship can promote healing.

Excerpt from *Risking Connection: A Training Curriculum for Working with Survivors of Abuse*, K.W. Saakvitne, L.A. Pearlman, S.J. Gamble, and Beth Tabor Lev, Sidran Press, 2000, p. 13.

Before You Begin

Although many trauma survivors find it difficult, now would be a good time to get a complete physical (medical) examination, especially if you have not had one in the past two years. This is important for at least three and possibly four reasons:

- Many medical illnesses (such as thyroid, diabetes, and seizure disorders) might mask or contribute to mental health conditions and interfere with appropriate psychological assessment and treatment. It makes sense to see your physician first to rule out any potential medical causes of your distress.

- If you are eventually going to see a psychiatrist for prescribing antidepressant, anti-anxiety or other symptom-reducing medications, the psychiatrist will require a current medical evaluation, and will want to consult with your personal physician.

- Posttraumatic stress disorder has both psychological and physiological symptoms. The best way to proceed toward recovery is to attend to medical and emotional needs in a simultaneous and integrated way. Ideally, your physician and your therapist should consult periodically about your progress.

- If you have a trusting relationship with a family doctor, internist or general practice physician, he or she might be a good source of referrals to a mental health specialist in your community.

Before you actually begin the process of selecting a therapist, it is important to have a working knowledge of the range of professional options (and there are many). It is important to remember that credentials do not necessarily ensure quality. Still, qualifications are a good starting point in evaluating a therapist, and should you ever have a harmful therapy experience, you may have some recourse through a complaint to a licensing body or professional association.

Types of mental health care providers: Alphabet Soup!

The words "therapist" and "counselor" are unregulated, generic terms. They can be used to refer to anyone providing treatment, and can be used as a title by anyone, with no requirement of special training.

In some states, anyone can hang a shingle on their door and practice "therapy" with nothing more than a high school diploma, so beware of "therapists" with unfamiliar titles.
No ethical professional therapist should mind being asked about his or her educational or professional backgrounds. You should likely stay away from individuals who don't have at least a Master's degree (e.g. M.S., M.S.W., C.S.W., M.A.).

Psychologists

In the U.S., Doctors of Philosophy (Ph.D.), Psychology (Psy.D.), or Education (Ed.D.) must complete at least four years of post graduate school, however, only those who have been licensed can call themselves psychologists. Clinical psychologists are specifically trained in assessing a client to determine the problem and to respond by providing treatment. In most states, if medication is needed in addition to therapy, a psychologist will refer the client to a psychiatrist for that aspect of treatment.

However, not all psychologists are experienced therapists. Some specialize in areas such as statistical research or industrial psychology, and may have little experience treating people. Also, don't assume that Ph.D. always indicates a psychologist. Many people have earned Ph.D. degrees in unrelated academic fields, and may decide to practice therapy without being clinically trained or licensed.

Social Workers

Clinical Social Workers (CSW) usually have earned at least a Masters' Degree (two years of graduate school) and some may have doctoral degrees. Clinical Social Workers credentials may vary by state, but these are the most common: B.S.W. (Bachelor's of Social Work), M.S.W. (Master's of Social Work), A.C.S.W. (Academy of Certified Social Workers), or D.C.S.W. (Diplomate of Clinical Social Work. Although there are exceptions, most licensed clinical social workers generally have an "L" in front of their degree (e.g. L.C.S.W.).

Marriage and Family Therapists and Professional Counselors

Marriage and Family Therapists (LMFT), and Professional Counselors (LPC) may have two years of graduate school and have earned at least a Masters' Degree such as: M.A. (Master of Arts), M.S. (Master of Science) or M.Ed. (Master of Education). Marriage and Family Therapists have additional specialized training in the area of family therapy.

Professional Counselors, most typically drug or alcohol abuse specialists -- C.A.C. I, II, or III (Certified Addiction Counselors) -- may have a variety of more generalized training in the area of psychology and counseling. A *Counselor* may or may not have a master's degree. Counselors are trained for supportive therapy. They usually focus on behavioral problems not clearly classified as mental illnesses. Counseling is usually less intensive than psychotherapy.

Many other categories of professionals also provide mental health care services in private practices or in agencies.

Pastoral Counselors are clergy, who have the credentials M.Div. (Master of Divinity) or Th.D. (Doctor of Theology) and have a degree from a seminary or rabbinical school, with additional training in therapy.

Psychiatric Nurses and Nurse Practitioners comprise a growing segment of mental health treatment professionals. They display the credentials R.N. (Registered Nurse), R.N.P. (Registered Nurse Practitioner) or M.S.N. (Masters of Science in Nursing). A Psychiatric Nurse Clinical Specialist is a registered nurse with a master's degree who has been trained in individual, group, and/or family psychotherapy.

Psychiatrists, M.D. (Medical Doctors), complete a medical degree like any other physician, followed by a four-year psychiatry specialty. Psychiatrists' fees are likely to be the highest of all mental health providers. In this day of managed care, psychiatrists rarely provide "talk therapy". It is generally not necessary for a person with a trauma disorder to use a psychiatrist as a primary therapist. However, for those who have complex or co-occurring medical and mental health conditions, a psychiatrist has the advantage of being a trained M.D. Psychiatrists often work together with other non-medical psychotherapists to provide prescription and medication management services when needed.

The term ***psychoanalyst*** refers to any therapist trained in or practicing in the Freudian or analytic styled psychodynamic approach.

Hypnotherapist refers to anyone trained in or practicing hypnosis. A twelve-step *Sponsor* or a *Mentor* can provide support for those seeking help, but they cannot take the place of a psychotherapist.

A 1997 *Consumer Reports* readers survey showed people in therapy generally rated psychologists, clinical social workers, and psychiatrists about as equally effective. Marriage counselors were rated significantly worse, according to patient's rating of their own improvement.

In general, the most helpful therapists are:

- genuine,
- willing to share information about themselves as helpful and appropriate,
- have respect and a high positive regard for their clients,
- are warm and empathic,
- responsive and hopeful,
- have firm boundaries but are not domineering.

Helpful therapists also have:

- a variety of clinical skills to address the specific needs of the client;
- an understanding of the power imbalance that exists in therapy and a willingness to work towards empowerment of the client;
- a view of the client as the expert on his or her own life and as an active partner in therapy.
- awareness of their own biases and the limits of their skill, and willingness to refer you to other professionals if necessary.

Consumers of mental health services have contributed to the following list of things to look for in a therapist:

- Find a therapist you feel comfortable with. Therapy is not an easy process and your therapist is not there to be your friend.
- Find a therapist who respects your individuality, opinions, and self.
- Find a therapist who will not get upset if you disagree with what they have said, but instead encourages you to express yourself when you do not agree.
- Find a therapist who never minimizes your experiences and always respects your feelings.
- Find a therapist who will not try to force you to talk about things that you might not be ready for.
- Find a therapist that does not spend time talking about their own problems. Those sessions are for you, not your therapist.
- Find a therapist who wants neither a friendship nor a sexual relationship with you outside of your counseling sessions.
- Find a therapist who is more than willing to discuss problems that might arise between the two of you within the therapist/client relationship.
- Find a therapist who will help teach you new and healthier ways to cope.
- Find a therapist who will never make you feel like a failure or cause you to believe they are disappointed in you if you have a slip or a relapse.

Objectives of Therapy to Address Trauma Issues

Effective psychotherapy for trauma survivors usually involves helping the survivor maintain safety, manage symptoms, and work through the traumatic experience(s). While the techniques employed vary, the primary goals of psychotherapy for trauma survivors are:

- to examine the role of the traumatic experience in the context of the person's life, currently and historically
- to make meaning of the experience
- to learn skills to manage symptoms and to develop alternative ways of coping
- to build or rebuild the ability to trust within a relationship in order to view the world as an increasingly tolerable place to function

There has been a lot of controversy about therapy that focuses on memories of past trauma. Because the nature of traumatic stress is to distort memory in a variety of ways (remembering too much about traumatic experiences or too little, and in some cases both), therapeutic discussions of the meaning of past events are important. It is not necessary to use special techniques to discover hidden memories of violence or abuse. In the course of addressing problems in current daily function, the opportunity to discuss past events and the ability to recall them will evolve naturally as part of therapy.

Types of Therapy

There are many approaches to therapy, and most good therapists are trained in several and use them in combination. Approaches may be long or short-term, and may be focused primarily on the past or on the present, but all should aim to alleviate distress, and help clients learn how to acquire more effective coping strategies.

Psychodynamic approaches attempt to help the client discover the origins of the problem in the past as well as how it affects life today. A ***Behavioral*** approach tends to focus on changing current behavior with little emphasis on past events. The ***Cognitive*** approach focuses on changing the client's way of thinking, and a ***Family Systems*** approach aims to change unhelpful patterns in families.

Formats for therapy include individual (or one-on-one) therapy, couples' therapy, family therapy, and group therapy. Some therapists use a combination of these formats.

Today, many therapists describe their work as Eclectic, meaning that they draw from a wide variety of approaches in order to best meet the needs of each individual client. Research indicates that the quality of the therapeutic relationship is often more important than the particular methods employed. In therapy for traumatic stress, the relationship is particularly important, as rebuilding interpersonal trust is

often a key objective of treatment. The most important thing to remember is that your needs are paramount; choose a therapist whose approach seems most appropriate for you.

Getting Referrals

You can begin the process by getting referrals. REMEMBER: when choosing a therapist, you are a consumer of service, and it is your right to shop around.

First, make a list of names of two or three therapists from whom to choose. Your family doctor may be able to make a referral for you, although doctors may not know therapists who have particular experience with trauma survivors. Sidran Foundation has a list of therapists around the world who have made a commitment to addressing the needs of trauma survivors. We would be happy to provide names of therapists in your area, from which you can choose. Referral agencies or a women's resource center in your area may also be able to assist you in your search.

You might also ask people you know who've been in therapy to make recommendations. A therapist who's right for someone else may not be right for you, but someone you trust who has actually worked with a particular therapist can share very helpful information.

The Interview

When interviewing a potential therapist, keep in mind your needs and goals for therapy, as well as the particular qualities you feel are important in a therapist. We often hear about the need for a "match" when selecting a therapist and there is a lot to be said for feeling comfortable with the person you choose. Although your objective is not to build a friendship with the therapist, you will be spending a lot of time together, and you will need to feel comfortable enough to discuss sensitive, confidential thoughts and feelings.

Don't forget (or avoid) talking about money. You need to know before you start how you are going to pay for treatment. Therapists may take a variety of insurance payments: private insurance, Medicare, or state medical assistance; others will offer a payment plan or work on a sliding scale, based on what a client can afford. Rarely, a therapist may offer to do "pro bono" work (treat one or a few clients at no charge). As appealing as this may seem, it is not really a good idea, and may under some circumstances be unethical. This dynamic reinforces the power imbalance that is inherent in the therapy relationship, and the client may come to feel the "debt owed" interferes with therapy.

After the first meeting with the potential therapist, you will need to ask yourself some questions: Did you feel comfortable and able to begin discussing your problems? Did the therapist seem to understand what you were talking about? Did you feel your concerns were taken seriously and that you were treated with respect? Were

the two of you in general agreement about the problem and your expectations for therapy? Were you satisfied with the therapist's answers to your questions? Did you feel that you could grow to trust and work with this person?

Pay attention to your intuition; choosing a helpful therapist will require trusting your own thoughts and feelings. Remember that you are a consumer of a service and that it is your right to choose a therapist who best meets your needs.

Taking Stock

Throughout the course of therapy, you will need to be mindful that your work is productive and continues to be helpful. In helpful therapy relationships, the client feels understood and supported, and while therapy is not always a comfortable experience, there should be a sense of trust and warmth.

If you don't feel respected, valued or understood, or if your experience is being minimized or distorted, it may be a sign that your therapy is not working. If you feel there is something wrong in your therapy, or if you get upset or angry with your therapist, discuss it in your session. If your therapist discounts your feelings or responds in a defensive manner, you can choose to switch to a different, more respectful therapist.

If you are working with a helpful therapist, you will begin to be able to better recognize and understand your feelings, thoughts and behaviors. You will also begin to develop new, more effective coping strategies, and you should have a sense of change and increased satisfaction in your life. Over time, you should begin to feel more and more independent and able to use the skill and insights you are learning in therapy to solve your own problems.

How do I choose a helper?

Below you will find a list of questions that may help you interview helpers to determine who suits your needs the best. You may find it helpful to take this list with you on interviews along with a pad of paper to record your information.

Questions:

1. What are your credentials?
2. What are your specialties?
3. What professional organizations to you belong to?
4. How long have you been conducting therapy?
5. What experience have you had in treating traumatic stress conditions?
6. How do you approach treatment of traumatic stress conditions?
7. What do you charge?
8. Do you accept insurance? If so, what kinds?

9. Do you have a sliding fee scale? If so, how is payment determined?
10. Do you bill people, or is payment expected at the time of the session?
11. How do you protect client confidentiality? Who (besides you) will have access to my files?
12. How long is each session? Are there exceptions to this?
13. Has anyone ever lodged a formal complaint against you?
14. Have you ever been censured by a professional organization?
15. If I were in crisis, would I be able to reach you? How do you handle crises?
16. What is your policy about missed sessions?
17. What is your policy about physical contact with clients?
18. What is your policy about contact outside of the session?
19. Do you arrange vacation coverage?
20. What happens if one of us decides to terminate without the other's agreement?
21. Do you think you can help me?
22. Is there anything I should know about your services that I didn't think to ask about?

My impressions: check all that apply

- ❑ I felt safe and reasonably comfortable
- ❑ I felt understood and taken seriously
- ❑ I was treated respectfully
- ❑ We agreed about the nature of the problem
- ❑ This feels like it could be a good "match"
- ❑ My questions were answered adequately
- ❑ My treatment goals were addressed
- ❑ This individual is clinically qualified
- ❑ I can afford it
- ❑ I can get there with reasonable ease

Overall impression:

- ❑ Good
- ❑ Fair
- ❑ Poor

TREATMENT OF PTSD*

Introduction

This fact sheet describes elements common to many treatment modalities for PTSD, including education, exposure, exploration of feelings and beliefs, and coping skills training. Additionally, the most common treatment modalities are discussed, including cognitive-behavioral treatment, pharmacotherapy, EMDR, group treatment, and psychodynamic treatment.

Common Components of PTSD Treatment:

Treatment for PTSD typically begins with a detailed evaluation, and development of a treatment plan that meets the unique needs of the survivor. Generally, PTSD-specific-treatment is begun only when the survivor is safely removed from a crisis situation. For instance, if currently exposed to trauma (such as by ongoing domestic or community violence, abuse, or homelessness), severely depressed or suicidal, experiencing extreme panic or disorganized thinking, or in need of drug or alcohol detoxification, addressing these crisis problems becomes part of the first treatment phase.

- Educating trauma survivors and their families about how persons get PTSD, how PTSD affects survivors and their loved ones, and other problems that commonly come along with PTSD symptoms. Understanding that PTSD is a medically recognized anxiety disorder that occurs in normal individuals under extremely stressful conditions is essential for effective treatment.
- Exposure to the event via imagery allows the survivor to reexperience the event in a safe, controlled environment, while also carefully examining their reactions and beliefs in relation to that event.
- Examining and resolving strong feelings such as anger, shame, or guilt, which are common among survivors of trauma.
- Teaching the survivor to cope with post-traumatic memories, reminders, reactions, and feelings without becoming overwhelmed or emotionally numb. Trauma memories usually do not go away entirely as a result of therapy, but become manageable with new coping skills.

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* Modified from a National Center for PTSD Fact Sheet, http://www.ncptsd.org/facts/treatment/fc_treatment.html. Information is presented for educational purposes only. It is not a substitute for informed medical advice or training. Do not use this information to diagnose or treat a mental health problem without consulting a qualified health or mental health care provider. All information contained on these pages is in the public domain and may be copied and distributed without restriction. For more information, telephone 802-296-5132 or email ncptsd@ncptsd.org.

Therapeutic Approaches Commonly Used to Treat PTSD:

- ***Cognitive-behavioral therapy (CBT)*** involves working with cognitions to change emotions, thoughts, and behaviors. Exposure therapy, is one form of CBT unique to trauma treatment which uses careful, repeated, detailed imagining of the trauma (exposure) in a safe, controlled context, to help the survivor face and gain control of the fear and distress that was overwhelming in the trauma. In some cases, trauma memories or reminders can be confronted all at once ("flooding"). For other individuals or traumas it is preferable to work gradually up to the most severe trauma by using relaxation techniques and either starting with less upsetting life stresses or by taking the trauma one piece at a time ("desensitization").

  Along with exposure, CBT for trauma includes learning skills for coping with anxiety (such as breathing retraining or biofeedback) and negative thoughts ("cognitive restructuring"), managing anger, preparing for stress reactions ("stress inoculation"), handling future trauma symptoms, as well as addressing urges to use alcohol or drugs when they occur ("relapse prevention"), and communicating and relating effectively with people ("social skills" or marital therapy).

- ***Pharmacotherapy*** (medication) can reduce the anxiety, depression, and insomnia often experienced with PTSD, and in some cases may help relieve the distress and emotional numbness caused by trauma memories. Several kinds of antidepressant drugs have achieved improvement in most (but not all) clinical trials, and some other classes of drugs have shown promise. At this time no particular drug has emerged as a definitive treatment for PTSD, although medication is clearly useful for the symptom relief that makes it possible for survivors to participate in psychotherapy.

- ***Eye Movement Desensitization and Reprocessing (EMDR)*** is a relatively new treatment of traumatic memories which involves elements of exposure therapy and cognitive behavioral therapy, combined with techniques (eye movements, hand taps, sounds) which create an alteration of attention back and forth across the person's midline. While the theory and research are still evolving with this form of treatment, there is some evidence that the therapeutic element unique to EMDR, attentional alteration, may facilitate accessing and processing traumatic material.

- ***Group treatment*** is often an ideal therapeutic setting because trauma survivors are able to risk sharing traumatic material with the safety, cohesion, and empathy provided by other survivors. As group members achieve greater understanding and resolution of their trauma, they often feel more confident and able to trust. As they discuss and share coping of trauma-related shame, guilt, rage, fear, doubt, and self-condemnation, they prepare themselves to focus on the present rather than the past. Telling one's story (the "trauma narrative") and directly facing the

grief, anxiety, and guilt related to trauma enables many survivors to cope with their symptoms, memories, and other aspects of their lives.

- ***Brief psychodynamic psychotherapy*** focuses on the emotional conflicts caused by the traumatic event, particularly as they relate to early life experiences. Through the retelling of the traumatic event to a calm, empathic, compassionate and non-judgmental therapist, the survivor achieves a greater sense of self-esteem, develops effective ways of thinking and coping, and more successfully deals with the intense emotions that emerge during therapy. The therapist helps the survivor identify current life situations that set off traumatic memories and worsen PTSD symptoms.

Psychiatric disorders commonly co-occurring with PTSD

Psychiatric disorders commonly co-occurring with PTSD include: depression, alcohol/substance abuse, panic disorder, and other anxiety disorders. Although crises that threaten the safety of the survivor or others must be addressed first, the best treatment results are achieved when both PTSD and the other disorder(s) are treated together rather than one after the other. This is especially true for PTSD and alcohol/substance abuse.

Complex PTSD

Complex PTSD (sometimes called "Disorder of Extreme Stress") is found among individuals who have been exposed to prolonged traumatic circumstances, especially during childhood, such as childhood sexual abuse. Developmental research is revealing that many brain and hormonal changes may occur as a result of early, prolonged trauma, and contribute to difficulties with memory, learning, and regulating impulses and emotions. Combined with a disruptive, abusive home environment which does not foster healthy interaction, these brain and hormonal changes may contribute to severe behavioral difficulties (such as impulsivity, aggression, sexual acting out, eating disorders, alcohol/drug abuse, and self-destructive actions), emotional regulation difficulties (such as intense rage, depression, or panic) and mental difficulties (such as extremely scattered thoughts, dissociation, and amnesia). As adults, these individuals often are diagnosed with depressive disorders, personality disorders or dissociative disorders. Treatment often takes much longer, may progress at a much slower rate, and requires a sensitive and structured treatment program delivered by a trauma specialist.

RECLAIMING YOUR POWER DURING MEDICATION APPOINTMENTS WITH YOUR PSYCHIATRIST*

Meeting with a psychiatrist during "medication appointments" is usually a very disempowering experience. The meetings usually 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.

1. **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.

2. **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.

3. **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.

4. **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.

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means thoughtfully planning and following through with medication trials, medication reductions and/or medication withdrawal.

5. **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, and so forth. 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.

6. **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 he/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 nontechnical 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.) or Instant Psychopharmacology (Ronald Diamond, published by W.W. Norton) or Toxic Psychiatry (Peter Breggin, published by St. Martin's Press) or 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). If you have access to the Internet there are lots of resources including these:

- Dr. Bob's Psychopharmacology Tips at http://uhs.bsd.uchicago.edu/~bhsiung/tips/tips.htmll.
- Healthtouch, with an excellent data base of over 7,000 prescription and over the counter drugs at http://www.healthtouch.com/level1/p_dri.html.
- Medline at http://www/ncbi.nlm.nih.gov/pubmed.

Strategy #2: Learn to think differently about yourself.

1. **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, or perceived, 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, constipation, loss of sex drive, double vision, or the like, trust your perception. Don't let others tell you that such side effects are "all in your head." Check with the pharmacist, or with friends who have used the drugs, and check the books or the Internet. Chances are that you are not the first person to have these drug effects.

2. **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 the 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.

3. **Your questions are important.** Anyone who has been on psychiatric drugs for a period of time is probably going to ask these 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?
- 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.

1. **Most psychiatrists are too busy for our 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.

2. **Psychiatrists often have conflicting interests.** It would be comforting to think that psychiatrists were serving our individual interests. But this assumption would be naive. 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 he/she is working under. In other words, some psychiatrists receive their paychecks from managed care corporations that require them to prescribe one type of drug rather than others that are expensive. If this is the case, we should have this information!

3. **Sometimes psychiatrists are wrong.** Most psychiatrists do not encourage us to seek second opinions regarding diagnosis, medications, or other somatic treatments such as 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!

4. **Psychiatrists are not experts on 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, or similar experiences, 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.

1. **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/she does or does not do. In order to set an agenda it is important to define your immediate goals. Possible goals might include starting medication, discussing a medication change, 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 trial. Try, if possible, to set one goal for each meeting.

2. **Organize your thoughts and concerns.** I have also 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. A copy of this meeting preparation guide is available through the National Empowerment Center.[6]

3. **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. A guide to recording your medication and/or self-help trial is available through the National Empowerment Center.

4. **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 side effects, what should I do about it?

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[6] Available through the National Empowerment Center by calling 1-800-POWER-2-U.

- How can I contact you if, during this medication trial, I have questions or concerns I want to check out with you?

5. **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.

1. **Bring a note pad and pen to the meeting.** Most of us have had the unnerving experience of talking to a psychiatrist while he/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.

2. **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.

3. **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 bring two copies of a one-page, written statement of my agenda, concerns, and observations 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 the 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. For a sample copy of an opening statement, contact the National Empowerment Center.

4. **Bring a friend or advocate.** Many people bring a friend or support person when they see a dentist or have a physical exam. 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. If you would like a free information packet with a guide to meeting preparation, organizing your own medication/self-help trial, and a sample meeting agenda statement, just call our toll free number (1-800-POWER2U) and we'll be glad to send you one.

HOW TO TALK WITH YOUR DOCTOR ABOUT YOUR MEDICATIONS*

Questions:

1) I feel (choose what applies):

dizzy	can't sit still	difficulty with sexual functioning
tired	stiff	discharge from breast/nipple
hungry	legs shake	skin rash or acne
nauseous	blurry vision	sunburned easily
wired (can't sleep)	dry mouth	headache
a bad taste in my mouth	constipation	hand tremor, shakiness
my hands tingle	diarrhea	difficulty urinating

movements I can't help (arms, head, face)

How can we change either the dose of kind of medication I am taking so this doesn't bother me so much? Sometimes medication dosages can be adjusted without having to stop them altogether. Reducing the dose may reduce side effects of make them go away. For many conditions there are a number of medications that can be used that have different sets of side effects. One of them may produce side effects that bother us less.

2) **If I can't stand the side effects how do I get my doctor to listen to me?** Don't just stop taking your medications, but you need to be assertive on this point. If you let your doctor know that the side effects are so unpleasant that you might stop taking the medication if they don't go away, your doctor will probably work with you. However, when we start a medication there is a period of time when side effects are worse. Have patience through this time, but ask your doctor how long you can expect it to go on before your body gets used to the meds. The final point is not to "cry wolf" about this. Reserve this alternative for time when you really can't stand it.

3) **Will I become addicted to the medicine?** Only with benzodiazepines is there a risk of developing "tolerance" or need to increase the dose to get the same effect over time. That is why benzodiazepines are prescribed cautiously, and usually only for a short time.

4) **What happens if I stop taking my medicine without telling my doctor?** Many medications can have very unpleasant side effects if stopped abruptly. The main case where stopping abruptly would cause a life-threatening condition is with benzodiazepines. However, it is never a good idea to just stop taking medication without consulting a doctor.

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* Wisconsin Coalition for Advocacy (June 1996). Advocacy Training Manual (pp. 123-124). Community Mental Health Protection & Advocacy Project. Please contact for permission to reprint, http://www.w-c-a.org.

5) **Do I have to stop gradually or all at once?** Most often, gradual reduction is recommended. If we develop a serious side effect, the doctor should stop the medication immediately or very quickly if it is safe to do so.

6) **Will I have to take it all my life?** Those of us with "treatment resistant mental illness" (who have several episodes of psychosis, or who have had to try several medications before we found one that worked) will probably have to take psychiatric-related medication all of our lives. Because of this, clear doctor-to-patient and patient-to-doctor communication is crucial, especially about side effects. It is also important to do what we can for ourselves by eating right, exercising, sleeping on a regular schedule and doing relaxation exercises. All of these "wellness" activities can reduce our need for medication.

7) **What happens if I forget to take my medication?** Usually, if we forget to take medication and are a couple of hours or half a day late, it is recommended that we take the dose when we realize we have missed it. Then we should resume our regular schedule. If the dose missed is more than half a day late, we should not double it or take additional medication. We should simply pick up at the next scheduled dosage and tell the doctor if we feel any symptoms that bother us.

8) **What if I leave town and forget to bring my medicine?** If we leave town without our meds we should find an open pharmacy (many towns have 24 hour pharmacies) and call our psychiatrist to have our prescription telephoned in.

9) **What happened if I run out and the pharmacy is closed?** Many pharmacies have an emergency telephone number. Find out what it is and put it in some place where you can easily find it (like our "Emergency Contacts" sheet). If that doesn't work, you can call your hospital emergency room.

10) **If I run out of medicine and my friend or family member has the same medication, can I take theirs?** Do not take other people's medications! They may be a different brand, dosage, age, or even type of medication (the kind of medication in the bottle may not be the same as what is on the label). Call your doctor and get him or her to phone in a prescription.

11) **Do I have to take medicine just because the doctor says so?** Those of us on Mandatory Outpatient Treatment (MOT) are ordered by a court to take the medications prescribed by our doctor. We do not have the legal right to refuse medications. For all of the rest of us, if we want to refuse medication, we need to make sure we understand what the medications are supposed to be doing for us, the risks of wither taking or not taking them, and the alternative treatments available. If we are able to demonstrate to a court that we understand all of those things, and the court does not feel we will become a danger to ourselves or others, we do have the right to refuse to take medication.

However, in deciding to try going off medication, many of us have found it is essential to work it out with those folks who are our "support team". That includes our doctor, case manager, family, roommate, and good friends. We have found that making sure those who care about us learn about our meds, their side effects and

signs of relapse helps everyone approach this in a calmer way, and respond quickly and effectively if things start to go wrong.

TAKING MEDICATION SAFELY*

A woman who has dealt with chronic mood swings for many years and has finally been well for several years says, "I have learned as much as I can about the medications I take. I am very in tune with my body and this helps me in discussions with my doctor. I have read everything I can find about these medications in books, medical journals, the Physician's Desk Reference, *psychiatric drugs books, and newsletters. I also learn what I can from television and videos."*

The decision to use psychiatric drugs to treat your mood disorder is a decision only you can make. Your decision should be based on the best information available from health care professionals who are truly experts in this area and from your own research. Lack of information can lead to misuse of medication or cause harmful interactions between drugs.

This chapter will help direct your research strategy and will explain how to approach drug therapy in a way that offers you optimal benefits and maximum safety.

Choosing the appropriate medication regime takes time and persistence. Your medication must be tailored to you since your response to a particular medication, and the side effects you experience, are physiologically unique. Just because a member of your support group reports excellent success with Prozac, for instance, does not mean that you will find it helpful. I know that lithium causes me to experience severe tremors, yet a friend of mine can take it without getting them.

Seventy-three percent of the individuals who responded to the research questionnaire for my study said they use psychotropic (mood-altering) drugs to help them keep their moods stable. Of that group, 80 percent said the medication gives them at least some relief from symptoms. Some use long-term medication therapy, which they complement with self-help strategies to enhance their medical treatment. Others use medications for the short term to help strategies to enhance their medical treatment. Others use medications for the short term to allow time to work on issues, set up systems, learn management techniques, and make lifestyle changes that promote and enhance wellness. Some people sense that their moods are too unstable at present to allow them to do this work without the biological support medications can provide.

The most commonly used medications by people in the study were lithium, other mood stabilizing medications, and a wide variety of antidepressants. Some people also take antipsychotic medications and medications that address specific problems such as sleep and anxiety.

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* Copied with permission from New Harbinger Publications. Mary Ellen Copeland (1994). Living Without Depression & Manic Depression: A Workbook for Maintaining Mood Stability (pp. 49-67). Oakland, CA www.newharbinger.com.

In some cases the physician is unable to find any medication or combination of medications that relieves symptoms. In other cases, people who find that psychotropic drugs are effective opt to forego them for the following reasons:

- They fear the long- or short-term side effects.
- They feel medications diminish their quality of life.
- They feel that the medications interfere with normal sexual function, memory, intellectual capacity, coordination, vision, digestion, and so on.
- They feel like a failure if they have to use medications to manage their life.
- They have ethical reasons for refusing medications.
- They experience intolerable side effects.

Other people chose not to use medication because they are uncomfortable with the idea of using any medication for the rest of their lives. Some people in my study said lifelong drug therapy makes them feel like they have an incurable illness.

You may have your own reasons for not taking psychotropic medications. What are they?

_____

_____

_____

Given your reasons, is your decision in your best interest? If you are unsure, read on.

Non-Drug Therapies

Psychotropic drugs are not the only therapy available to you. Your health care professional may recommend non-drug therapies such as electroshock treatments or light therapy. See the section on seasonal affective disorder in chapter 5.[7] Find out as much as you can about any recommended therapy before you give your consent. Make several copies of the treatment form that begins on the next page so that you can record the information you obtain. Be sure to add this information to your personal medical files.

[7] This refers to the book Living Without Depression & Manic Depression: A Workbook for Maintaining Mood Stability

Treatment Information

Treatment name: _____

Other possible names of this treatment: _____

How does this treatment work? _____

_____

_____

What do you expect it to do? _____

_____

_____

How long or how many treatments will it take to achieve that result?

_____

_____

_____

How often will I have this treatment? _____

Where will I have it? _____

What are the risks associated with taking this treatment?

_____

_____

_____

What kind of effectiveness track record does this treatment have?

_____

_____

_____

What possible short-term side effects does this treatment have? -

_____

_____

_____

What possible long-term side effects does this treatment have?

Is there any way to minimize the chances of experiencing these side effects? If so, what are they?

Are there any dietary or lifestyle suggestions or restrictions when using this treatment?

Why do you recommend this particular treatment?

Have you had other patients that have used it? If so, how have they done?

How is this treatment monitored?

Do you have any printed information on this treatment I can have to study?

Where can I get more information about this treatment?

What tests will I need prior to this treatment?

How often will I need these tests while having this treatment?

What symptoms indicate that the treatment should be changed or stopped?

Making an Informed Choice

Since you are the one who ultimately has to live with the effects of your treatment, don't leave the decision to your doctor. You may need to do your own research so you can intelligently discuss your options with your professional health care team. You may even wish to keep up with the latest scientific research by subscribing to relevant newsletters or journals. People in my study said they found this helpful.

Follow the lead of the individual in my study who said:

I have learned everything I could about the medications I take. This has taken personal long-term research. I read the Physician's Desk Reference, and cross-reference that with other sources of information. And I also ask a ton of questions and record the responses and any information acquired. I know that these drugs can cause damage if not monitored carefully. I feel as if I know more than the doctor. It is my body and I always like to know what I am putting in my mouth.

If you don't do your own investigation, you could unwittingly injure yourself. My experience with lithium illustrates this point. When I was taking lithium, I wasn't aware of how important it was for me to maintain body fluids. A brief episode of acute gastrointestinal symptoms caused severe tremors. Fortunately, a quick trip to the emergency room for intravenous replacement fluids alleviated the problem.

Lithium Toxicity. The shaking I experienced was a sign that lithium had reached toxic levels in my body. Diarrhea and nausea also signal the onset of lithium toxicity. If you experience any of these symptoms, contact your physician immediately.

Because lithium is commonly used to treat manic depression and, less commonly, depression, let me share with you the dynamics that lead to lithium toxicity.

Lithium toxicity is an ever-present danger whenever you lose copious amounts of body fluids, whether through sweating when you are working outdoors on a hot day, or when you're sick with diarrhea or vomiting.

Your body needs a certain amount of sodium to perform normal body functions. When you sweat and lose body fluids, you lose sodium along with the fluid. The body tries to maintain its salt level by adjusting the filtering system in the kidneys so less salt then usual gets lost.

According to an informative report in the newsletter of the Topeka, Kansas, Depressive and Manic Depressive Association, "lithium and sodium are almost identical and your kidneys can't tell the difference between the two. When the kidney's filters hold in salt, they also conserve lithium that would normally pass out of your system. That means the amount of lithium in your body remains high. This can cause symptoms of lithium toxicity including shaking, nausea, and diarrhea."

You can counter this effect by using plenty of salt in your diet when you are working outdoors in the heat. Taking extra salt may make the symptoms disappear quickly, because the salt will cause the filters in the kidneys to release the accumulated lithium. (If you are on a sodium-restricted diet, be sure to consult your physician about the right course of action.)

If you get a flu bug, or diarrhea, contact your doctor for advice on how to manage lithium through your illness. Do NOT stop taking lithium or adjust the dosage without consulting your physician first.

Do make sure you are getting plenty of fluids. It is also essential to get your thyroid tested, on a regular basis, since lithium can sometimes cause hypothyroidism. (For more information on lithium, contact the Lithium Information Center which is listed at the end of the chapter.)

Working With Your Doctor

The more you know about your own body and the idiosyncracies of the medication you are considering, the better off you are. To ensure your safety, a thorough medical examination should precede any new medication regime. Have your health care professionals make sure that you have no health conditions that could be worsened by a particular medication.

A good medical history will help your doctor choose wisely from the available array of drugs. When you are discussing your options, be sure to tell your doctor if any of the following apply to you:

- You are allergic to any medicine.
- You are breast feeding.
- You have seizures, high blood pressure, heart disease, or glaucoma.
- You are taking blood pressure medication, antihistamines, or any other (prescription or nonprescription) medicine.
- You have any other medical problems.

Questions To Ask Your Doctor

When you are considering any new treatment regime, there are two immediate issues to consider: length of treatment and length of time on medication before you will feel better. There is currently much discussion in the mental health field about the pros and cons of long-term use of antidepressant and mood stabilizing medications. The potential for long-term damage is reason enough to seek out a physician who is an expert on psychotropic drugs and has up-to-date information on the most current scientific research.

Be sure to ask how long it will take before you'll notice positive effects from the medication. You may not see any improvement for several days to several weeks. Don't expect to feel better overnight. The improvement is likely to be gradual. In fact, most medications take from two to three weeks to work.

Beginning on the next page is a form for recording pertinent information about particular medications. (Before you record any information on this form, you may want to make several copies of it for later use for other proposed medications or treatments.)

Using Medicine Safely

Learn everything you can about a recommended medication before you decide if it is the right one for you. Find out what systems of the body it affects, the risks of using it, whether there are side effects that can accompany this drug, and if there are food, vitamins, or other drugs you should avoid when taking this drug. Don't be afraid to ask these same questions of your pharmacist.

Medication Information

Generic name:

_____

Product name:

_____

Product category:

_____

Suggested dosage level:

_____

How does this medication work?

_____

_____

_____

What do you expect it to do?

_____

_____

_____

How long will it take to achieve that result?

_____

_____

_____

What are the risks associated with taking this medication?

_____

_____

_____

What is the effectiveness record of this medication?

What short-term side effects does this medications have?

What long-term side effects does this medication have?

Is there any way to minimize the chances of experiencing these side effects? If so, what are they?

Are there any dietary or lifestyle suggestions or restrictions when using this medication?

Does this medication cause any adverse reactions when taken with certain other medications? If so, describe them.

Why do you recommend this particular medication?

Have you had other patients that have used it? If so, how have they done?

How is this medication monitored?

What tests will I need prior to taking this medication?

How often will I need tests while on the medication?

What symptoms indicate to you that the dosage should be changed or the medication stopped?

Do you have any printed information on this medication I can have to study? Where can I get more information about this medication?

If you are already taking medication for depression or manic depression, make sure you follow the guidelines below. Check off those steps that have been or need to be taken.

1. You are under the supervision of a physician who is an expert in the use of psychotropic medications. (Your physician has the responsibility to fully inform you of all risks and benefits of any medication prescribed, whether you ask or not.)

   ☐ I am under the supervision of a physician who has the appropriate expertise.

   ☐ I need to find such a physician.

2. You know the potential side effects of any medication prescribed for you and take personal responsibility to know what goes into your body and what the known side effects are.

3. You have the regular blood tests required for the medication you are taking.

   ☐ I have been given the regular tests required for the medication I am taking.

   ☐ I need to check with my doctor and make sure I am having the required tests for the medication I am taking.

4. You do not change the amount of medication you are taking or stop taking the medication without consulting your physician. (Systems for medication changes and discontinuation vary with each medication and must be monitored carefully to avoid potentially serious reactions. If you are having severe side effects and cannot reach your physician, contact another physician who your doctor have previously recommended as a backup, and ask how to deal with the situation.)

   ☐ I understand that it is dangerous for me to adjust medication dosages in any way. If I feel a change is necessary, I will be in touch with my physician.

5. You are completely honest with your physician if you have forgotten to take the medication a few times, or didn't renew the prescription on time. This will allow your physician to accurately assess the effectiveness of the medication.

6. You give your supporters copies of this information and choose one person you trust who can help you find out what you need to know about medication when you are not well enough to do it yourself.

   ☐ I have designated _____to help me when I cannot do it myself.

Making Your Pharmacist Part of Your Safety Team

Consider your pharmacist an active member of your health care team and choose someone who takes a personal interest in you. Also make sure that the pharmacy has a good reputation and a computerized record-keeping system.

I know from personal experience that this is very important. There was a time when I was taking Tegretol, a medicine to control severe mood instability. The medicine helped stabilize me and I was doing well. When symptoms started to recur, my doctor tested the level of the drug in my blood and found that it was below the therapeutic level. He assumed that my body was not absorbing the drug, so he increased the dosage.

At the same time, I ran out of the old prescription and had it refilled. I immediately began having symptoms that indicated I was taking too much Tegretol. When I investigated, I found that the old prescription had been recalled because that batch was not at the correct strength. Unfortunately, my pharmacy—which was part of a large drugstore chain—hadn't taken the trouble to notify me. It took me four months to recover from the effects of changing the strength of the medication and taking too strong a dose. Since then, I've used a small but reputable pharmacy where the pharmacist knows me well.

A good pharmacist will set up a system on the computer that will keep track of how many pills you have left in an old prescription when you change medications. If you ask, the pharmacist could require you to return leftovers before giving you the new prescription. This can eliminate a person's ability to hoard pills for a suicide attempt during a period of severe depression. Consider asking your pharmacist to set up this safeguard for you if you have ever been suicidal or thought of hoarding pills. Check the steps below that you have taken or need to be taken.

- ☐ My pharmacist takes a personal interest in me, and the pharmacy itself is reputable and uses computerized record-keeping systems.
- ☐ I need to find a pharmacy that meets all of the above conditions.
- ☐ I have asked my pharmacist to assist me in preventing suicide by monitoring my purchase of medications.

Taking Responsibility for Your Treatment Regime

Taking medication can become so routine that it is hard to remember whether or not you have taken your daily dose. One way to make sure you do is to take an empty egg carton, mark each egg container with a day of the week, and fill that container with the medicine you need for that day. A quick glance at the carton will tell you whether or not you've taken that day's medicine. Other people prefer setting out their medicine for the day in cups—one for morning medicine, one for afternoon medicine, and so on. Pharmacies also sell small containers that can be used.

Some people find that making a simple checkmark on a daily chart does the trick for them. Others make a daily note in a log designed to provide an accurate long-term record of medication use and symptoms experienced.

If you need to take your medication at a certain time each day, a watch with a timer or a small inexpensive timer that you can purchase at your pharmacy can be a helpful reminder.

Don't be hard on yourself if you forget to take your medication. It is not a personal failure. We all forget. Establish a system for yourself that will most easily resolve the problem. When you realize you have missed several doses of medication, check with your physician to see if you should take the missed doses or continue with the regular single dose.

Guidelines for Taking Medications

Here are some additional safeguards. They were developed by Mary Moller, MSN, RN, CS, of The Center for Patient and Family Mental Health Education in Nine Mile Falls, Washington.

1. Take all medications exactly as prescribed.
2. If the medication may make you drowsy or less alert, curtail activity accordingly.
3. Do not share your medication with others. You never know how your medication could affect another person.
4. Keep all medications in a cool, dry place. Bathroom moisture tends to destroy the effectiveness of medication.
5. Keep all medications out of reach of children and pets.
6. Be sure you have enough medications before vacations and holidays.
7. If you are pregnant or planning on becoming pregnant, tell your physician. Many medications can have a harmful effect on a pregnancy, especially during the first three months.
8. If you are planning to use an over-the-counter medication such as a cold medicine, ask the pharmacist if it can be safely taken with your prescription drugs.
9. Keep all medication in the original bottle. Never mix two medications in one bottle.
10. Remember to tell all your doctors and dentists that you are on medication.

Managing Side Effects

Unfortunately, some psychiatric medications that are very effective can cause unwanted side effects. Many of them are manageable. But if you find that you have checked any of the dangerous side effects listed below, report them immediately to your doctor. Don't wait!

- ☐ blurred vision
- ☐ rash or hives
- ☐ nervousness, irritability, shakiness
- ☐ wanting to sleep all the time
- ☐ confusion
- ☐ fainting, seizures, or hallucinations
- ☐ nausea and vomiting
- ☐ slurred speech
- ☐ lack of coordination, stumbling
- ☐ jerking of arms and legs
- ☐ seizures or fainting
- ☐ complete stopping of urination
- ☐ changes in sex drive, impotence
- ☐ rapid or irregular heartbeat
- ☐ sore throat or fever
- ☐ insomnia
- ☐ restlessness, incoordination
- ☐ giddiness
- ☐ numbness in hands or feet
- ☐ mental confusion
- ☐ stomach pains
- ☐ swelling of hands or feet
- ☐ ringing in ears
- ☐ large increase in urination
- ☐ infection
- ☐ changes in menstrual cycle

Some common side effects of psychotropic drugs include constipation, dizziness, dry mouth, dry skin, headaches, impotence, irritable bowel syndrome, loss of libido, nausea, tardive dyskinesia and dystonia, thought deficits, tremors, water retention, and weight gain. These side effects can often be managed.

You may find that the side effects you experience are most severe when you begin the medication. After your body adjusts, they may diminish or disappear. I've noticed that I tire easily during the first several weeks I begin taking a new medication. I deal with it by adjusting my schedule so I have less to do and can get more rest.

There are other safe, simple, and effective ways to deal with such side effects. For instance, one man reported that he takes his tricyclic antidepressants with three or four crackers and a full glass of water one or two hours before his bedtime. This helps him avoid stomach upset.

Another says she manages the side effects with exercise, good diet, and a homeopathic medicine for nausea. She accepts her side effects but watches to make sure they don't get out of hand. When they do, she takes it as a warning of an impending episode.

In general, anything that contributes to your overall sense of well-being tends to lessen the incidence and severity of medication side effects. This includes a high-fiber, low-fat diet, plenty of liquids (check with your doctor to find out how much liquid you need with the medication you are taking), daily exercise, and the regular

use of stress-reduction techniques. You may find, as many people do, that when life begins to feel "out of control," side effects tend to get worse. See chapter 5, "Developing a Lifestyle That Enhances Wellness," for ideas on how to adjust your lifestyle to enhance your sense of well-being.

Here are ways to minimize or eliminate specific side effects:

Constipation. Many psychotropic medications cause dryness, which increases the likelihood of constipation. This can be prevented by eating high-fiber foods such as whole grains, fruits and vegetables and by getting daily exercise. Using a dietary fiber additive that contains psyllium husks and drinking a quart to a gallon of liquid daily helps elimination. Nonpresciption stool softeners may also be helpful.

Diminished sex drive and impotence. When you tell health care professionals about diminished sex drive and impotence, they may minimize the importance of this medication side effect. This is not fair. Clearly people who take medications for psychiatric symptoms deserve full sexual expression just like everyone else. Some people decide to switch medications or discontinue their use because of this side effect. Your health care professional should take it seriously.

Dry mouth. According to the National Institute of Dental Research, dry mouth is a side effect of more than 400 commonly used medications, including those prescribed for depression. This occurs because you are not producing as much saliva as you need. Saliva is an important plaque fighter and tooth hardener, and its absence can lead to gum disease and tool decay. The National Institute of Dental Research suggests asking your dentist about an artificial saliva to moisten your mouth.

Some people in the study said they eat hard candies to eliminate dry mouth. However, this also causes dental problems. There are many sugarless candies on the market which can be used as a substitute.

Again, adequate fluid intake is essential to successfully manage this side effect. Small amounts of water or juice taken frequently help.

Dry skin. The use of liberal amounts of creams, ointments, and oils helps to alleviate dry skin. There are many unscented products that are acceptable to everyone. Use as little soap as possible and rinse it off quickly. Adequate fluid intake and a healthy diet also help.

Headache and dizziness. Headaches and dizziness may be caused by blood pressure changes. Get up and down slowly. Avoid extreme temperature changes. Consult your doctor about this problem.

Insomnia. Adjusting the time of day when you take medications may help to reduce sleep problems. Some medications help you to sleep, so they can be taken an hour or two before bedtime. Those that keep you awake should be taken in the

morning. See chapter 5, "Developing a Lifestyle That Enhances Wellness," for more information on how to get to sleep.

Irritable bowel symptoms (chronic diarrhea alternating with episodes of constipation, and often accompanied by cramps and gas). Symptoms of irritable bowel syndrome are reported by many people who take psychiatric medications or who have mood instability. It is not clear whether the symptoms are caused by the medications, the stress of the instability, or something else.

A study volunteer said, "This can be very disruptive. I've gone to a gastroenterologist and he did a colon examination, found nothing, and prescribed Immodium, which is now available over-the-counter. It works pretty well to stop the spasms and is easier to carry around and quicker acting that Kaopectate. Immodium is actually a narcotic, but it normally doesn't cross the blood-brain barrier, so you can't get high from it."

Dietary fiber additives that contain psyllium husks and an adequate intake of fluid help but do not generally cure this condition. My gastroenterologist says that it takes two weeks to determine how effective it is to use a fiber additive daily. She also recommends Immodium for those times when diarrhea is inconvenient.

A high-fiber, low-fat diet-accompanied by stress reduction techniques, exercise, and adequate rest-may also help to control symptoms.

Nausea. If you experience nausea, taking medication with food or milk may help.

Tardive dyskinesia and dystonia. Antipsychotic drugs such as Haldol, Loxitane, Mellaril, Moban, Navane, Prolixin, Thorazine, Tindal, Trilafon, Stelazine are sometimes prescribed to relieve symptoms of major depression and manic depression. Cumulative exposure to these medications can cause severe side effects, including tardive dyskinesia and tardive dystonia.

Tardive dyskinesia causes uncontrollable movement, varying in degree from occasional minor twitches to severe involuntary movement. The most commonly affected area is the face, where there may be abnormal movements of the tongue, jaw and muscles around the mouth and eyes. Involuntary movement of the arms, legs, and torso may also be involved. Occasionally a person will experience an irregular breathing rate, speech irregularities, and weight loss.

Tardive dystonia is characterized by muscle spasms that result in involuntary, painful, sustained twisting and distortion of body parts.

These side effects can continue even after you have stopped taking the medication. The movements can be permanent. There is no treatment for tardive dyskinesia or tardive dystonia.

The risk of getting these disorders is about 30 percent for people who have taken the medication for a total of five years (it is estimated that 400,000 to one million people are affected). Occasionally people who have used these medications for a short time develop symptoms. The risk increases as you get older.

Before you begin taking such medication, you should clearly understand the benefits and risks involved. The more you know about the benefits and risks of antipsychotic medications, the more you will be able to make appropriate choices about your treatment. You have a right to know this information, and the prescribing health care professional has a responsibility to help you understand the risks. If you are not well enough to understand the benefits and risks, have a trusted support person assist you in making this decision.

If you take or are considering taking neuroleptic medications, be alert to any signs of tardive dyskinesia.

- Notify your doctor as soon as you notice any unusual movement.
- Have a tardive dyskinesia checkup every three months. (These checkups must be done by your physician, and take from five to ten minutes.)

It is important to remember that tardive dykinesia can be masked by the sedating effect of the medication. When the medication is discontinued, the symptoms may increase.

To reduce symptoms of tardive dyskinesia and tardive dystonia, take the following steps:

- Ask your physician about using high doses of certain benign agents such as Vitamin E, choline, or lecithin.
- Use relaxation techniques and stress management daily. (Stress worsens symptoms.)
- Soak in a hot bath or whirlpool.
- Use moist application of heat, or use ice to help reduce acute symptoms and pain.
- Exercise to improve posture and strengthen muscles.

Tremor. Mild to severe tremor affects many people who take psychotropic medications. Adequate rest and strict attention to fluid intake may alleviate this problem somewhat. Relaxation exercises also help.

Soaking in a warm bath sometimes reduces tremors. The effect is enhanced by use of a whirlpool. There are inexpensive whirlpool units available that fit in the bathtub.

Thought deficits. Some people experience thought and memory problems when taking certain psychiatric medication (these are also a symptom of depression). A person in the study said, "One frustrating problem I have is difficulty coming up with a word I want to use—it feels like it gets 'stuck' inside my head." His doctor attributed the problem to the anticholinergic—or drying—properties of his medication. I remember not being able to remember a question long enough to give an answer.

It helps to stay calm when these problems arise. The problem worsens if you get anxious or agitated, but it is minimized if you have a relaxed attitude. It also helps if the people you associate with are understanding and nonjudgmental.

If you are anxious or agitated, do the relaxation exercises in chapter 16, "Responding to Symptoms of Depression," and chapter 18, "Responding to Symptoms of Mania."

Water retention. If you are troubled by water retention, tell your doctor. You doctor may want you to limit your salt intake.

Weight gain. Weight gain is a common side effect of many medications. If you know a particular medication may cause weight gain, make needed dietary adjustments when you begin using it rather than waiting until after you have gained the weight. It's easier to keep from gaining weight than to lose weight. Weight gain can be minimized by focusing on a diet high in complex carbohydrates (vegetables and grains) and low in simple sugars and saturated fats. See chapters 5,[8] "Developing a Lifestyle That Enhances Wellness," for diet information and the resource list below and at the end of chapter 5 for more information on weight control and dietary issues.

Resources

American Automobile Association, *RX for Safe Driving*. Heathrow, FLA: American Automobile Association.
This free booklet describes how drugs affect your ability to drive. To obtain copy, send a self-addressed, stamped envelope to RX For Safe Driving, Mail Stop 600, 1000 AAA Drive, Heathrow, FL 32746-5063.

Barnhart, E. (1993) *Physicians Desk Reference*. Oradell, NJ: Medical Economics Co.
This book is updated annually and contains technical information on medications. The book isn't all that accessible to the average reader, but it will give you the information you need to ask your health care professionals the right questions.

[8] This refers to the book Living Without Depression & Manic Depression: A Workbook for Maintaining Mood Stability.

Gorman, J. (1991) *The Essential Guide to Psychotropic Medications.* New York: St. Martin's Press.
Check out medication recommendations in this up-to-date reference.

Griffith, H. (1993) Complete Guide to Prescription and Non-Prescription Drugs. New York: Body Press/Perigee.
This comprehensive reference provides complete information about prescription and nonprescription medications and explains the differences between brand-name medications and generics, and describes the standards for safe medication use.

John Hopkins University (1993) John Hopkins Handbook of Drugs. Baltimore: John Hopkins University Press.
Gives information about medications and their side effects to physicians, pharmacists, and the Food and Drug Administration.

Mondimore, F. (1990) *Depression: The Mood Disease.* Baltimore: Johns Hopkins.
A good, medically oriented reference.

Schein, J., and P. Hansten (1993) *The Consumer's Guide to Drug Interactions.* New York: Collier Books.
This book provides essential information on the effects of taking several different kinds of medications.

Wolfe, S., R. Hope, and Public Citizen Health Research Group (1993) *Worst Pills Best Pills II.* NY: Pantheon.
Lists 364 commonly prescribed medications including 119 which should not be used by some people and 113 that should be used only in a very limited way.

Yudofsky, S., R. Hales, and T. Ferguson (1991) *What You Need To Know About Psychiatric Drugs.* New York: Grove Weidenfeld.
This book contains easy-to-understand information about all psychiatric medications, including tranquilizers, sedatives, sleeping pills, anti-anxiety medications, mood stabilizers, antidepressants, and antipsychotics.

Diet and Medication

Rosenthal, N. (1993) *Winter Blues.* New York: Guilford Press.
There is a section in the appendix of this book that gives helpful dietary advice that is useful to people who are taking psychotropic medications.

Fanning, P. (1990) *Lifetime Weight Control.* Oakland, CA: New Harbinger Publications.
A different and very useful approach to weight loss.

Hoffman, R. (1988) *The Diet-Type Weight-Loss Program.* New York: Simon & Schuster.

This book helps you determine the diet that will work for you based on your lifestyle and eating habits. I found it to be very useful in developing a weight control program for myself.

Kirschenbaum, D. (1994) *Weight Loss Through Persistence*. Oakland, CA: New Harbinger Publications.
An excellent, long-term weight loss program based on up-to-date scientific findings.

Turner, K. (1987) *The Self-Healing Cookbook*. Grass Valley, CA: Earthtones Press.
This delightful cookbook shows you how to easily change your style of cooking to one that enhances your wellness. It includes a section on foods that actually help you lose weight.

Organizations

For more information on Tardive Dyskinesia, contact:

Tardive Dyskinesia/Tardive Dystonia National Association
4244 University Way Northeast
PO Box 45732
Seattle, WA 98145-0732

National Institute of Mental Health
Neuroscience Center at Saint Elizabeth's
WAW Building, Room 201
2700 Martin Luther King Jr. Ave. Southeast
Washington, DC 20032

For more information on lithium contact:

Lithium Information Center
Department of Psychiatry, University of Wisconsin
Center for Health Services
600 Highland Ave.
Madison, WI 53792
(608) 263-6171
This center is a storehouse of information on lithium.

Betty Blaska (1990). Hospital and Community Psychiatry, 41, 9, 993-998.

THE MYRIAD MEDICATION MISTAKES IN PSYCHIATRY: A CONSUMER'S VIEW*

Many consumers of mental health services suffer needlessly as a result of being given the wrong medication or the wrong dosage of the right medication or from other mistakes involving medication. The author, a consumer of mental-health services for many years, discusses seven common medication mistakes: incorrect prescribing as a result of misdiagnosis, excessive dosages of medications, too many drugs, downplaying side effects, overlooking the consumer's expertise, discouraging consumers from learning about their medications, and the prescription-sheet relationship between psychiatrist and consumer. She concludes that although mental health professionals should listen more attentively to consumers, consumers bear the major responsibility for seeing that mistakes in their medication are corrected. Thus they must continue to speak up, raise questions, and keep informed.

I am a consumer of mental health services—a 20-year veteran of the mental health system. Over the past two decades I have had 13 psychiatric hospitalizations, have taken 18 or more different medications, have been a victim of electroconvulsive "treatment", and have had opportunities to talk to and suffer with psychiatric service consumers of all kinds, in hospital settings, in support groups, and in consumer networks. I know too well the grave errors that can be committed when psychotropic drugs are prescribed.

Realizing early on that psychiatry was an inexact and far-from-perfect science that demanded a "buyer beware" stance, I bought my own copy of the Physicians' Desk Reference and studied psychiatric journals. I have also become active in the mental health service consumer movement.

Being a moderate in the movement, I believe psychotropic medications have a legitimate place in the array of treatment options. I am not antipsychiatry, or antimedication. However, I have seen and experienced a great deal of abuse and many mistakes. For example, there has been an alarming trend recently toward involuntary treatment that usually involves prescribing drugs and nothing else. Too many of these patients get seen by a physician only once a month or once every three months, even though more frequent intervention in their drug regimen may be needed. In addition, the general public often become alarmed when mentally ill people quit taking their medication for reasons the public doesn't understand.

I think it is important to remind both the public and professionals that many mistakes are made in prescribing drugs, that psychotropic drug side effects can be

* Betty Blaska (1990). Hospital and Community Psychiatry, 41, 9, 993-998. Used with permission of the publisher.

harrowing, and that mentally ill patients can become frustrated and quit taking their medication when mistakes aren't corrected. In addition, I think consumers who take medications—and most of us will continue to take them—need frequent admonitions to become assertive in our psychiatrist-patient relationships and to take the lead in voicing complaints, observations, and preferences.

The Consumer's perspective

Recently I was asked to present the consumer's perspective on taking psychotropic medications to a graduate sociology class. In my speech I discussed the hazards of taking psychotropic medication. The following synopsis of my speech outlines seven common mistakes in prescribing medication for psychiatric patients.

Mistake 1: Incorrect prescribing as a result of misdiagnosis. Psychopharmacology practitioners' gravest error is misdiagnosis. It usually results in prescribing medications that not only don't help but that also worsen a patient's condition. It is curious that a person who is misdiagnosed rarely gets rediagnosed, despite failure after failure with drug trials predicated on the misdiagnosis.

I suffered from depression from age 12 to 18. When admitted to a university hospital in 1969 at age 18, I acquired the labels "schizoid personality" and "schizophrenia." After drug trials on Melaril and Stelazine, side effects of akinesia and akathisia, worsened depression, and suicide attempts, I threw the pills out and went to a general practitioner—a nonpsychiatric physician—at the university student health clinic. Not mentioning my previous three hospitalizations, I told him that I was a little depressed and needed Elavil (that was what my hospital roommate had said helped her). And it worked! After six years of depression, I felt normal for the first time.

That was back in 1969. But I'm dismayed to see that clinicians are continuing to misdiagnose today, with concomitant prescribing errors and refusal to reassess the diagnoses. In particular, it seems that people with affective disorders are often misdiagnosed with schizophrenia, perhaps because the flat affect and social withdrawal of depression look like the negative symptoms of schizophrenia, and the hallucinations and inflated delusions of mania look like the positive symptoms of schizophrenia.

Mental health consumers will attest to the difficulties associated with medications used for the treatment of schizophrenia. One such difficulty is depression. Johnson[1] found a greater likelihood of depression in patients who were prescribed higher doses of neuroleptics, an excess of depression among patients with drug-induced extrapyramidal symptoms, and an akinesia syndrome simulating depression in 7.5 percent to 12.5 percent of patients free from extrapyramidal symptoms.

In a recent report of several case studies, symptoms worsened in patients with psychosis who were treated with neuroleptics.[2] These patients acquired neuroleptic-induced catatonia, early neuroleptic malignant syndrome, and severe drug-induced parkinsonism; they also became actively suicidal. From the author's discussion I

gathered that in these cases, which involved relatively young females, it was more fruitful to view the illness as delusional depression than as psychosis with affective features because neuroleptics in modest doses actually worsened the syptomatology.

Mistake 2: Excessive dosages of medications. In my 20 years as a mental health service consumer, I have seen the suffering of people—too many people—who were loaded up on high doses of drugs. Excessive drug dosages usually results in side effects that may completely obviate the intended therapeutic effect. The "therapeutic window" posits that a given drug is effective for a given patient only within a certain range that is neither too high nor too low.

Cohen and Baldessarini[3] discussed what they called an "apparent development of tolerance to the therapeutic effects of antidepressants," followed by attempts to recover an initially positive drug effect by repeatedly administering higher and higher doses. Asberg and colleagues[4] suggested that therapeutic failure might be due to "a too low or too high plasma level" of antidepressant drugs. Likewise, Whyte and associates[5] suggested that "high plasma levels of antidepressants in patients may be associated with rather poor clinical responses."

Although the problem in such cases may be the excessive dosage, the patient gets the label "treatment resistant." Hence the doctor should take note and be more careful, keeping the patient at a low dose a bit longer before raising it. More attention should be paid to the possibility that excessive dosage is causing the treatment failure.

I claim that the patient is the best authority on what dose is effective and what dose is too high. Allergies and chemical sensitivities seem to be fairly common among psychiatry patients, and it may be that the chemical sensitivity to psychotropic medications is especially acute. Because of this sensitivity, prescribers should routinely obtain detailed medication histories form the patient or the family.

In actual practice, persons often seem to do better on lower doses. Corona and colleagues[6] compared patient response to the tricyclic anti-depressant amitriptyline at 50, 100, and 150 mg per day and found that "the better clinical response was with 50 mg doses." Linden and colleagues[7] studied private psychiatrists' drug prescribing and found that amitriptyline was regularly prescribed at low doses. Although the recommended daily range for this drug was 150 mg to 300mg, psychiatrists in this study reported good results with prescriptions of 30 mg to 50 mg per day. Johnson[8] found that among patients with Beck Depression Inventory scores of 11 or more, only 25 percent were prescribed more than 75 mg of a tricyclic antidepressant per day. Thirty-five percent were prescribed less than 75 mg per day—a dose most would call "subtherapeutic." Perhaps we need a revision of what is considered an effective dose of tricylic antidepressants in view of what psychiatrists are commonly prescribing and what patients are experiencing.

Ziegler and associates[9] suggested the possibility "that at some level of total tricylic the therapeutic effect begins to deteriorate" and concluded that "the widely accepted notion that 150mg/day of amitriptyline represents a therapeutic trial is not true for a large percentage of patients." Bridges[10], though, suggesting progressive

increases in antidepressant dosages, with pauses to wait for an effect, conceded that "doses that are too high can be as ineffective as doses that are too low." He counseled that if high doses are found to be ineffective, "there is still the opportunity to observe the effect of a reduction." Furthermore, Moller and colleagues[11] have reported unfavorable responses with antidepressants at levels not only too low but also too high.

Why not start with a low dose of antidepressants and cautiously raise it only after no improvement is observed at that low dose? If persons who once responded favorably to an antidepressant stop doing so, even after successively higher doses, perhaps the therapeutic window for those individuals has been moved down the dosage axis. Doses that were once effective may now be too high for the sensitized individual. Alternatively, the patient's depression may have worsened, necessitating higher dosage.

In a recent report of four patients who responded to antidepressants with worsening depression and suicidal ideation not present before treatment, Damluji and Ferguson[12] noted the intensification of depressive symptoms in patients treated with "therapeutic" doses of antidepressants. I would submit that obviously therapeutic doses and therapeutic drugs vary quite widely among individuals.

People on antipsychotic medication are certainly not immune to errors in dosage. In a study of people with schizophrenia, Hogan and Awad[13] found that doses of fluphenazine had been much higher in a group of patients who committed suicide compared with the doses of a matched control group. They hypothesized that increasingly higher doses of fluphenazine may have been given to "counter symptoms that were actually drug induced: the reduced spontaneity, diminished emotional tone, and lethargy of akinesia, or the restlessness, misperceived as anxiety, of akathisia." The drugs may actually have been the culprit in their mortality.

Rifkin[14] pointed out the risk of responding to akinesia with an increased dosage of neuroleptic, a common practice because the condition may resemble negative schizophrenia symptoms. I share his concern about the proportion of persons with chronic schizophrenia who have "unrecognized akinesia, and to what extent [their] apparent symptoms of residual schizophrenia are iatrogenic—due to medical treatment." Also, I like his reminder to medical practitioners: "Our first obligation toward our patients is to do no harm."

Rapid neuroleptization—increasing the dose of neuroleptic rather quickly and aggressively—among new admissions with schizophrenia is being challenged. Miller and Tanenbaum[15] proved the success of using only 12 mg of haloperidol compared with nearly twice that dosage in two comparable populations of men with schizophrenia. They noted that the "desire to increase the speed, completeness, and quality of recovery may be an important factor" in rapid neuroleptization but reported no evidence that higher dosages accomplished these goals. They allowed that 12mg doses might be excessive and that effective treatment with even lower doses might be achievable.

Schulz and Pato[16] concluded in a recent review that "many patients in the United States have received higher maintenance dosed of neuroleptics than necessary." They emphasized the importance of trying to find the lowest effective dose for a given individual with schizophrenia because studies have demonstrated the "low doses may be as effective as routine doses of medication for maintenance of schizophrenia" and "quality of life of patients on lower doses is better than those of standard doses."

A review by Manchanda and Hirsch[17] indicated that a group of patients with schizophrenia on low-dose neuroleptics had the same rates of relapse (22.4 percent) as patients in a high-dose group (20.2 percent). The disadvantages for the high-dose group were more anxiety and depression and a higher score on measures of retardation and akathisia. The reviewers concluded that "the concept of low-dose maintenance medication should gain popularity—among both patients and physicians." Last, in a study of relapse rates in patients with schizophrenia maintained on low-dose neuroleptics, Farone and colleagues[18] found that 12 of 16 patients who stayed in remission for a year after a 50 percent reduction in neuroleptic dose remained stable during a subsequent two year follow-up. In most instances their neuroleptic doses were below the "usual therapeutic range."

Mistake 3: Too many drugs. Often when one medication does not help an individual immediately, psychiatrists add a second, a third, or even more medications on the regimen. It is not unusual to see people diagnosed as having schizophrenia prescribed two or three neuroleptics concurrently, and then of course prescribed medication for the side effects of the neuroleptics. People with bipolar illness can be on lithium, carbamazepine or some other anticonvulsant (despite risk of neurotixicity), a neuroleptic, and an antidepressant. Sovner[19] described intraclass polypharmacy—the simultaneous prescription of more than one drug from the same psychotropic drug class—as "almost never acceptable", except transitionally, when switching from one drug to another. Polypharmacy is not inherently bad, but as the Alcoholics Anonymous dictum goes: keep it simple! In relation to psychiatric treatment that means the fewer the drugs, the better.

In the movie *Four Lives*, a documentary about people with bipolar affective disorder, a woman is given lithium for mania and comes out of the manic phase only to go into a depressive one. Her doctor adds an antidepressant, with no remission of depression but no return to mania. He pushes electroconvulsive therapy, but she refuses it. The doctor credits this refusal to "a denial of her illness," an assertion that is ill supported by the woman's own acknowledgements on camera.

The offending drug in this patient's case may have been the lithium. She was not depressed before the lithium; why not try eliminating it? From 20 percent to 40 percent of people with bipolar disorder do not respond to lithium alone.[20] Lithium induces hypothyroidism in some individuals, which is perceived as depression. For patients like this woman there are options other than lithium and an antidepressant, and certainly options other than electroconvulsive therapy. A low-dose neuroleptic may keep her out of mania as well as the lithium does, but without the depression.

Although there are times when two or more drugs may be better than one, the addition of a second drug is not always without complications. One report found that 17 percent of patients with bipolar illness taking both lithium and a neuroleptic developed neurotoxicity (delirium, extrapyramidal effects, or cerebellar effects).[21] Lithium doses were at "therapeutic" levels in both toxic and nontoxic patients, but neuroleptic doses were significantly greater in patients who became toxic. And high-potency neuroleptics were significantly more likely to result in neurotoxicity. The authors questioned whether the benefits of combining lithium with a neuroleptic outweigh the risks and suggested a combination of lithium with benzodiazepines as an alternative.

Mistake 4: Downplaying side effects. It is always wise to take the consumer's complaints of side effects seriously. Someone who complains about taking the prescribed medication is likely to have a legitimate reason. I will never doubt a person's objections to drugs because of the harrowing days I spent on Mellaril and Stelazine. I know what it's like to want to die rather than take those drugs at those doses.

A good example of a harrowing side effect is akathisia, which makes a person feel literally unable to sit still. It produces feelings of wanting to climb the walls, intense inner anxiety, and restlessness—a truly unbearable disease.

Drake and Ehrlich[22] reported two cases of impulsive suicide attempts, one by a young man on haloperidol and the other by a woman on fluphenazine, who perceived their symptoms of akathisia (increased anxiety, tension, agitation, restlessness, and psychosis) as a worsening of their illness and concluded that life was not worth living. The authors pointed out that "agitated delusional depression may be inadequately treated or made worse by antipsychotic medications."

Shear and colleagues[23] reported on two men with akathisia who committed suicide by jumping. The men had been experiencing akathitic muscle discomfort, agitation, fidgety feelings, and restlessness from neuroleptics (fluphenazine). Shaw and co-workers[24] reported akathisia, suicidal and homicidal ideation, paranoia, anxiety, tension, and agitation in a 43-year-old man on haloperidol. They suggested that his suicidal ideation may have been a direct pharmacological effect rather than secondary to the akathisia. Unfortunately, many consumers don't complain of drug side effects, especially akathisia, for the not-unfounded fear of having the dose raised. Szabadi[25] reported that "not infrequently the akathisia is made worse by an *inappropriate* [author's emphasis] increase in neuroleptic dosage." Akathisia can be misdiagnosed as an agitation symptom of psychiatric illness, to which the clinician gives more drugs, rather than being seen as an adverse drug reaction, to which the response is less drug[26].

Although Adler and associates[27] prescribed treating neuroleptic-induced akathisia by lowering the neuroleptic dose or switching to lower potency neuroleptics, we've seen both a shift toward higher doses of neuroleptics over the years and a shift from low-potency neuroleptics to higher potency ones.[28] The loser in these trends is the consumer.

A small proportion of patients on antidepressants also experience akathisia[29]. Restlessness, agitation, and hyperactivity have been reported in 10 percent of patients taking antidepressants, and some of these cases represent antidepressants-related akathisia. Psychotropics are not benign drugs.

The doctor who brushes aside patient complaints of side effects is being merciless. A mental health professional who is concerned only with behavioral control and not with the patient's disease will not be an effective and empathic clinician. Furthermore, such professionals should drop all illusions about their "profession."

Mistake 5: Overlooking the consumer's expertise. Many of the mistakes previously described come down to one thing: a refusal to see the consumer as an expert on his or her illness. The person with schizophrenia is the authority on his schizophrenia. The person with bipolar illness is the authority on her mood swings. No one should try to subvert these experts' testimony on their illnesses or on their reactions to drugs. Mental health professionals who do not approach a client in this light cannot help that client.

Research has demonstrated that consumers are able to identify what is happening to their bodies when ingesting chemicals. Solovitz and colleagues[30] found that patients were able to discriminate adverse drug reactions from other types of symptoms to a significant degree. In their study, patients correctly attributed symptoms to the target drug 69 percent of the time. And in Manchanda and Hirsch's study[17] of relapse with low-dose neuroleptic maintenance therapy, the authors concluded, "Indeed, the patient may be as able as the psychiatrist in predicting whether he can function without the benefit of continued maintenance treatment."

In my work with consumers in Wisconsin, I am increasingly amazed that the consumers who do the best in maintaining their quality of life and their ability to function on the job are those who consistently push for the fewest drugs and the lowest doses possible—sometimes in the absence or outright contradiction of their psychiatrists.

Mistake 6: Discouraging consumer education. I know from the sociology of medicine that specialized jargon and a unique body of knowledge cloak the profession in a mystique that allows mental health professionals a great degree of autonomy and power. That mystique is meant to keep the consumer out. But these are the 1990s. Consumers, and especially consumers of mental health services, are not buying it. We have rights, and we want to be heard.

I count among the best the psychiatrists who encouraged me to learn about my illness, to read the reference books and psychiatric journals, and to be knowledgeable about the drugs I was taking. There was the doctor who lent me books from his library, the one who recognized he had something to learn when I brought in the latest articles on carbamezepine several years ago, and the one who encouraged me to take his "Psychopharmacology Update" seminar.

Conversely, there was the doctor who arrogantly brushed aside the articles I found on monoamine oxidase inhibitors and weight gain, saying he didn't need to read

them. There were the ward nurses who wouldn't give me a pass to go to the medical library; they told me I "knew too much already." Finally, there was the resident who complained that I was "trying to play doctor" by reading the psychiatric journals.

It does the mental health professional little good and clients irreparable harm to restrict them from learning more about their illness, diagnosis, drugs, and especially side effects. I do not subscribe to the belief that warning patients of possibly dangerous side effects will cause them to magically acquire them. The benefits of having an informed consumer and good doctor-patient relationship outweigh the irritation that occasionally come with a "hypochondriac" who imagines side effects at the first suggestion of them.

The harm from not knowing about possible side effects is worse. I fell down a whole flight of stairs and later landed facedown on the ground when getting off a bus because I was experiencing muscle ataxia from lithium toxicity and didn't know it. No one had even warned me of lithium toxicity. Carbamazepine can lethally impair white blood cell production. Monoamine oxidase inhibitors interact with tyramine-producing foods to cause hypertensive crises. These potentialities require the consumer to be aware—and to beware. Again, psychotropic drugs are not so benign.

Mistake 7: The prescription-sheet relationship between psychiatrist and consumer. A prescription-sheet relationship describes what a consumer has with a psychiatrist who only prescribes drugs. Unfortunately, that's the relationship most of us consumers have with our psychiatrist. Economies of time and money have dictated that we see one professional for medications and another for therapy. Neither treats the "whole person," and neither is really able to do a great job of his or her half. Important clues can be lost when one is divided up so arbitrarily between soma and psyche. The physician needs to know about patient psychology—to see the whole picture of their lives—to understand the drugs' impact on them. The therapist has to consider patient physiology to know what apparently pasychogenic symptoms are in actuality adverse drug effects requiring a medication adjustment.

Conclusions

To eradicate or decrease these medications mistakes, the consumer must continue to raise questions, keep informed, and listen to his or her body. The medication mistakes I list are common. If consumers are aware that they are mistakes, we can then speak up to our psychiatrists. Professionals, for their part, need to listen to consumers more attentively. However, I hold consumers more responsible for correcting these errors, because I believe we must take responsibility for our lives and our treatment.

I applaud the court decisions that protect citizens' rights to accept or refuse medical interventions, including psychotropic drugs, if they are competent to understand the intended effects and the advantages or disadvantages. As long as there is no cure for psychiatric illness, as long as the biological theories are inexact, as long as drugs are an incomplete or imperfect treatment, as long as drug prescribing is still trial and error, and as long as clinicians continue to make mistakes in diagnosis and prescribing, we cannot humanely allow forced drugging.

To deny mental health consumers' participation in our own treatment decisions is to strip us of our rights as human beings, as citizens of a progressive and civilized society, and as adults. It is in denying this participation that psychiatry and society contribute to the stigma associated with being a "mental patient." Consumers are pressing for more rights. But we have the rights inherent to our citizenship in a free country. We need to assume responsibilities in line with those rights.

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COPING WITH FLASHBACKS*

What is a Flashback?

- The involuntary release of fears associated with a traumatic event which may be forgotten.
- A form of spontaneous age regression which is like reliving a specific traumatic event (often forgotten) from the past.

What Causes the Fears?

Any experience that feels threatening to the physical, emotional or spiritual body. Early fears are often related to the mother's fears. They may result from being an unwanted child, birth trauma or being nursed or fed mechanically. They may also be caused by being ridiculed, ignored or punished for expressing emotions such as anger, grief and fear and needs such as touching and the exuberant expression of love and creativity.

Other common causes of forgotten fears are:

- Sibling birth or abortion.
- Ridicule by anyone, including parents, teachers, siblings or peers.
- Parental conflict and divorce.
- Too much attention for the wrong things, such as illness or other dependencies.
- Too little attention for basic needs such as touch, approval and self-expression.
- Witnessing or experiencing emotional or physical abuse, including sexual abuse.
- Parental or sibling long-term illness, disability or death.
- Emotional absence of the caregiver due to addictive behaviors around alcohol, drugs (including prescribed), food, sex, religion, television, reading, sports, *etc.*

Why are Such Fears Forgotten?

Shock often accompanies trauma. Shock numbs pain, including painful memories. If we don't get help in working through a painful experience, we may block the memory of it in order to "keep going."

What are the Symptoms of a Flashback?

- Most flashbacks begin with a feeling of numbness similar to being in shock. This is the numbness that accompanied the original trauma. By habit, most flashbacks end here because a distraction (eating, drinking, reading, sleeping,

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TV, drugs, *etc.*) is used to keep going and to avoid the pain that's coming up. This is a key cause of addictive behavior.

- If the flashback continues, the numbness is often followed by the impulse to run away, to be alone. Many flashbacks end at this point, with resort to distracting behavior.
- If the flashback continues, there is a feeling of physical weakness and vulnerability, similar to the condition we are in when we are vomiting. Often there is involuntary trembling, rapid heart rate, panic, sweating, shortness of breath and a feeling of faintness. If the flashback is related to sexual or other physical abuse, the forgotten physical pain of that abuse may return at this point. At this point, it may be impossible to find any distraction that will interrupt the flashback.
- The physical weakness may be followed by deep emotional pain that feels unbearable.
- At this point, the person having the flashback may return in feeling and behavior to the age they were when the original trauma occurred. They may take an infantile or even fetal position, moaning or crying or gasping.
- An adult having a flashback may feel and look sick or "crazy."

What to Do if You're Having a Flashback.

- Keep breathing as deeply, slowly and steadily as you can.
- If you're with people you trust, let them know what is happening.
- If you're in a situation that does not feel supportive or appropriate, do the best you can to delay the flashback by staying in the numb state until you find a safe place.
- Do not drive or operate other machinery even in the numb state. It's best not to do anything you wouldn't do if you felt like you had to vomit.
- As soon as you can, put yourself in a safe and comforting place (soft lighting and soothing music, etc.).
- Curl up in a ball in a soft place (cozy blanket and pillows, etc.).
- If possible, summon a companion whom you trust and who understands flashbacks, who can remain very calm and who can provide appropriate and supportive touch and remind you to breathe (La Maze techniques are excellent during flashbacks!).
- Let out any sounds or cries or screams that want to come.
- Remember that you are attending to a part of yourself that has been neglected for a long time.

What to do if Someone You're With is Having a Flashback.

- Remain very calm, breathing steadily and slowly.
- Remind them to keep breathing.
- Decide if you are able to be completely present. If you are not, find someone who is.
- Even if you can be available, get some support for yourself if you can.
- Help them find a soft place and a comfortable position, wrap them up in a blanket with pillows, turn down the lights, put on soothing music, and stay very close, offering supportive touch if appropriate. (If the original trauma involved touch, it may not be appropriate.)
- Do not expect them to explain their behavior or even to use words. Encourage them to make any sound or movement they feel like making. Assure them that they are not sick or crazy and that the painful feelings will pass.

What to Do if You've Already Had at Least One Flashback.

- **Spend time with yourself and learn to nurture yourself.**
- **Create a support network** of people who understand flashbacks and who are willing to share the responsibility of supporting you. Make sure they all know each other's names and home numbers and times when they are most likely to be available. Make it clear that you only want their support when they are really available, otherwise you risk recreating the original trauma.
- **Join a self-help recovery group** that is appropriate for you. There are many such groups available and they are free. Make sure the group cultivates listening and doesn't try to fix you.
- **Find a professional caregiver** who is experienced in treating people having flashbacks. Make sure this caregiver is involved in their own recovery process. Make sure this caregiver is willing to cooperate with the support network you have created.
- **Shop for help carefully.** The risk of recreating your original trauma in any kind of self-help or therapy situation is very high.
- **Do not assume that anyone except you has the answer to your recovery.**
- **Remember: A flashback is your inner child trusting you with a life experience you have forgotten. Do the best you can to honor and nurture this trust.**

IDEAS FOR COPING WITH FLASHBACKS*

1. Tell yourself you are having a flashback and that this is okay and very normal in people who were traumatized as children (or as adults).
2. Remind yourself that the worst is over - it happened in the past, but is not happening now. The "child" inside you who was abused is giving you these memories to use in your healing and, however terrible you feel, you survived the awfulness then, which means you can survive and get through what you are remembering now.
3. Call on the "adult" part of yourself to tell your "child" that she is not alone, not in any danger now, and that you will help her get through this. Let your child self know it's okay to remember and to feel what she feels and that this will help her in healing from what had happened to her. However hard it is for you, she is communicating in the only way she can.
4. Try some of these ways of "grounding" yourself and becoming more aware of the present:
   - stamp your feet, grind them around on the floor to remind yourself where you are now.
   - look around the room, noticing the colors, the people, the shapes of things.
   - listen to the sounds around you: the traffic, voices, the washing machine etc.
   - feel your body, the boundary of your skin, your clothes, the chair or floor supporting you.
   - have an elastic band to hand (or on your wrist)—you can "ping" it against your wrist and feel it on your skin—that feeling is in the **now**, the things you are re-experiencing were in the past.
5. Take care of your breathing: breathe deeply down to your diaphragm; put your hand there (just above your navel) and breathe so that your hand gets pushed up and down. You can also count—to 5—as you breathe out and in. When we get scared we breathe too quickly and shallowly and our body begins to panic because we're not getting enough oxygen. This causes dizziness, shakiness and more panic. Breathing slowly and deeply will stop the panic.
6. If you have lost a sense of where you end and the rest of the world begins, rub your body so you can feel its edges, the boundary of you. Wrap yourself in a blanket, feel it around you.
7. Get support if you would like it. Let people close to you know about flashbacks so they can help you if you want them to. That might mean holding you, talking to you, helping you to reconnect with the present, to remember you are safe and cared for now.

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* Modified from a brochure by the same name from the Bristol Crisis Service for Women, available at: http://www.selfinjury.freeserve.co.uk/flash.html. For more information, please visit their web site at: http://www.users.zetnew.co.uk/bcsw, write: PO Box 654, Bristol BS99 1XH, or telephone 0117 925 1119.

8. Flashbacks are powerful experiences which drain your energy. Take time to look after yourself when you have had a flashback. You could have a warm, relaxing bath or a sleep, a warm drink, play some soothing music, or just take some quiet time for yourself. Your "child" and you deserve being taken care of, given all you went through in the past.
9. When you feel ready, write down all you can remember about the flashback and how you got through it. This will help you to remember information for your healing and to remind you that you did get through it (and can again).
10. Remember you are not crazy—flashbacks are normal and you are healing.

GUIDE TO DEVELOPING A WRAP — WELLNESS RECOVERY ACTION PLAN*

The following handout will serve as a guide to developing Wellness Recovery Action Plans. It can be used by people who are experiencing psychiatric symptoms to develop their own guide, or by health care professionals who are helping others to develop Wellness Recovery Action Plans.

This handout, or any part of this handout, may be copied for use in working with individuals or groups.

Getting Started

The following supplies will be needed to develop a Wellness Recovery Action Plan:

1. a three ring binder, one inch thick
2. a set of five dividers or tabs
3. a package of three ring filler paper, most people preferred lined
4. a writing instrument of some kind
5. (optional) a friend or other supporter to give you assistance and feedback

Section 1 - Daily Maintenance List

On the first tab write "Daily Maintenance List." Insert it in the binder followed by several sheets of filler paper.

On the first page, describe, in list form, yourself when you are feeling all right.

On the next page make a list of things you need to do for yourself every day to keep yourself feeling alright.

On the next page, make a reminder list for things you might need to do. Reading through this list daily helps keep us on track.

Section 2 - Triggers

External events or circumstances that, if they happen, may produce serious symptoms that make you feel like you are getting ill. These are normal reactions to events in our lives, but if we don't respond to them and deal with them in some way, they may actually cause a worsening in our symptoms.

On the next tab write "Triggers" and put in several sheets of binder paper.

On the first page, write down those things that, if they happened, might cause an increase in your symptoms. They may have triggered or increased symptoms in the past.

On the next page, write an action plan to use if triggers come up, using the Wellness Toolbox at the end of this handout as a guide.[9]

Section 3 - Early Warning Signs

Early warning signs are internal and may be unrelated to reactions to stressful situations. In spite of our best efforts at reducing symptoms, we may begin to experience early warning signs, subtle signs of change that indicate we may need to take some further action.

On the next tab write "Early Warning Signs." On the first page of this section, make a list of early warning signs you have noticed.

On the next page, write an action plan to use if early warning signs come up, using the Wellness Toolbox at the end of this handout as a guide.[10]

Section 4 - Things are Breaking Down or Getting Worse

In spite of our best efforts, our symptoms may progress to the point where they are very uncomfortable, serious and even dangerous, but we are still able to take some action on our own behalf. This is a very important time. It is necessary to take immediate action to prevent a crisis.

On the next tab write, "When Things are Breaking Down." Then make a list of the symptoms which, for you, mean that things have worsened and are close to the crisis stage.

On the next page, write an action plan to use "When Things are Breaking Down" using the Wellness Toolbox at the end of this handout as a guide.[11]

Section 5 - Crisis Planning

In spite of our best planning and assertive action, we may find ourselves in a crisis situation where others will need to take over responsibility for our care. We may feel like we are totally out of control.

Writing a crisis plan when you are well to instruct others about how to care for you when you are not well, keeps you in control even when it seems like things are

[9] This information can be found in the next article in this handbook.
[10] Ibid.
[11] Ibid.

out of control. Others will know what to do, saving everyone time and frustration, while insuring that your needs will be met. Develop this plan slowly when you are feeling well. The crisis planning form includes space to write:

- those symptoms that would indicate to others they need to take action in your behalf
- who you would want to take this action
- medications you are currently taking, those that might help in a crisis, and those that should be avoided
- treatments that you prefer and those that should be avoided
- a workable plan for at home care
- acceptable and unacceptable treatment facilities
- actions that others can take that would be helpful
- actions that should be avoided
- what my supporters should do if I am a danger to myself or others
- instructions on when the plan no longer needs to be used

DEVELOPING A WELLNESS TOOLBOX*

The first step in developing your own Wellness Recovery Action Plan, is to develop a Wellness Toolbox. This is a listing of things you have done in the past, or could do, to help yourself stay well; and, things you could do to help yourself feel better when you are not doing well. You will use these "tools" to develop your own WRAP.

Insert several sheets of paper in the front of your binder. List on these sheets the tools, strategies and skills you need to use on a daily basis to keep yourself well, along with those you use frequently or occasionally to help yourself feel better and to relieve troubling symptoms. Include things that you have done in the past, things that you have heard of and thought you might like to try, and things that have been recommended to you by health care providers and other supporters. You can get ideas on other tools from self-help books including those by Mary Ellen Copeland including *The Depression Workbook: A Guide to Living With Depression and Manic Depression,* and *Living Without Depression and Manic Depression: A Guide to Maintaining Mood Stability Depression, The Worry Control Book, Winning Against Relapse, Healing the Trauma of Abuse,* and *The Loneliness Workbook.* You can get other ideas from the audio tapes *Winning Against Relapse Program* and *Strategies for Living with Depression and Manic Depression.*

The following list includes the tools that are most commonly used to stay well and help relieve symptoms.

1. Talk to a friend—many people find this to be really helpful
2. Talk to a health care professional
3. Peer counseling or exchange listening
4. Focusing exercises
5. Relaxation and stress reduction exercises
6. Guided imagery
7. Journaling—writing in a notebook
8. Creative affirming activities
9. Exercise
10. Diet considerations
11. Light through your eyes
12. Extra rest

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13. Take time off from home or work responsibilities
14. Hot packs or cold packs
15. Take medications, vitamins, minerals, herbal supplements
16. Attend a support group
17. See your counselor
18. Do something "normal" like washing your hair, shaving or going to work
19. Get a medication check
20. Get a second opinion
21. Call a warm or hot line
22. Surround yourself with people who are positive, affirming and loving
23. Wear something that makes you feel good
24. Look through old pictures, scrapbooks and photo albums
25. Make a list of your accomplishments
26. Spend ten minutes writing down everything good you can think of about yourself
27. Do something that makes you laugh
28. Do something special for someone else
29. Get some little things done
30. Repeat positive affirmations
31. Focus on and appreciate what is happening right now
32. Take a warm bath
33. Listen to music, make music or sing

Your list of tools could also include things you want to avoid like:

1. alcohol, sugar and caffeine
2. going to bars
3. getting overtired
4. certain people

Refer to these lists as you develop your Wellness Recovery Action Plan. Keep it in the front of your binder so you can use it whenever you feel you need to revise all or parts of your plan.

A WELLNESS TOOL: DEVELOPING AND KEEPING A CIRCLE OF SUPPORT*

In the first column,[1] I described how to develop your own Wellness Recovery Action Plan. When you begin developing your Wellness Recovery Action Plan, you develop a list of wellness tools to be used in planning how you will keep yourself feeling well every day and how you will help yourself to feel better when you begin to feel badly. One of the most important wellness tools for many people is spending time with people you enjoy. They have found that regular contact with family members and friends who are supportive keeps them well. They have found that telling another person how they feel when they don't feel well can help them to feel better. This column will discuss the issue of support and describe things you can do to build yourself a strong circle of friends and supporters.

You may feel that you don't have any supportive people in your life, or that you have so few of these people that you feel lonely much of the time. You may feel that your lack of support and loneliness makes you feel sad or depressed some or most of the time. This problem may be worse if you live by yourself. Most people agree that they would benefit from having at least five close friends and supporters in their life that they really enjoy.

Everyone needs and wants to have friends. They enrich your life. They make you feel good about yourself and about being alive. Friends are especially helpful when you need special attention and care. A good friend is someone who:

- You like, respect and trust, and who likes, respect and trust you
- Accepts and likes you as you are, even as you grow and change
- Listens to you and shares with you, both the good and the bad
- You can tell anything to and know they will not betray your confidence
- Lets you express your feelings and emotions, and does not judge, tease or criticize
- Gives you good advice when you ask for it, assists you in taking action that will help you feel better, and works with you to figure out what to do next when you are having a hard time
- Lets you help them when they need it
- You want to be with, (but you aren't obsessed about being with them)

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[1] Refers to the previous article *Guide to Developing a WRAP—Wellness Recovery Action Plan.*

- Doesn't ever take advantage of you

You can probably think of some other attributes you would like from your friends.

You will find that some friends meet some needs and others meet other needs. Don't expect one friend to meet all of your needs for friendship and support. Appreciate your friends for the things you like about them and don't try to change them to better meet your needs.

Make a list of the people in your life that you feel closest to—those people who you would turn to in times of need. Is there something you could do to improve your relationships with these people? You could invite them to your home to visit, share a meal, play a game, watch a video, or share some other activity. You could do something nice for them or visit them when they are having a hard time.

Developing New Friendships

How do you reach out to others to establish friendships? This is not an easy task. You may find that you would feel more comfortable staying at home than going to an activity where you can meet other people. Almost everyone feels this way. Try to ignore those feelings and get out to activities in the community where you can meet other people—people with whom you might develop closer connections.

Meet potential friends and supporters by:

- Attending a support group. It could be a group for people who have similar health issues or life challenges, or a group for people of the same age or sex.
- Going to community events, taking a course, joining a church or civic group.
- Volunteering. Strong connections are often formed with people who are working together on projects of mutual interest or concern.

Some friendships develop casually. You may hardly be aware that your relationship with the other person is getting closer and more comfortable. More often it takes some special effort on someone's part to help the relationship grow. You could do this by:

1. Asking the person whom you like to join you for coffee or lunch, to go for a walk or to do something together you both enjoy;
2. Calling the person on the phone to share something you think they might be interested in;
3. Sending a short, friendly e-mail and see if they respond;
4. Talking with them when you see them about something of interest to both of you;
5. Helping the person with a project you are both interested in.

You may be able to think of some other enjoyable activity that the two of you could share. Go slowly. This will give you a chance to decide if this is really a person you want for a friend. And others may be intimidated if you "come on too strong". As you both enjoy each other more the friendship deepens. Notice how you feel about yourself when you are with the other person. If you feel good about yourself, you may be on the road to a fulfilling friendship.

Keeping Friendship Strong

Keeping your friendships strong needs consistent attention from you. There are many things you can do to help keep your friendships strong.

In addition, if you feel ready, you could become further involved if you choose by:

1. Like yourself. If you don't like yourself, don't feel that you have any value or don't think others will like you, you will have a hard time reaching out to people who may become friends.
2. Enjoy spending time alone. People who enjoy spending time alone and are not desperate to have people around all the time make better friends. Being desperate can drive others away from you. Fill time alone with activities you enjoy and that enrich your life. Perhaps a pet would help.
3. Have a variety of interests. Develop interests in lots of different things that make you an interesting person for others to be with.
4. Friendships must be mutual. Be there for your friends as much as they are there for you.
5. Listen and share equally. Listen closely to what the other person is saying. Avoid thinking about what your response is going to be while the person is talking. If a person is sharing something intense and personal, give them your full attention. Don't share an "I can top that" story. Be willing to listen to your friend share the details of a difficult time over and over again—until they have "gotten it out of their system".
6. Communicate as openly as you can. Tell your friends what you need and want and ask them what they want and need from you. Do not share so much information about details that the other person gets bored. Watch the response you are getting from the other person or people you are talking to so you can know if this is the right time to be sharing this, or the right subject for this person.

7. Avoid giving advice unless it is requested.
8. Never make fun of what the other person thinks or feels. Avoid judging, criticizing, teasing or sarcasm.
9. Never betray the confidence of a friend. Have a mutual understanding that anything the two of you discuss is personal is absolutely confidential, that you will not share personal information about each other with other people.
10. Have a good time. Spend most of your time with your friends doing fun, interesting activities together.
11. Stay in touch. Keep regular contact with your friends and supporters, even when things are going well.
12. Don't overwhelm the person with phone calls or other kinds of contact. Use your intuition and common sense to determine when to call and how often. Don't ever call late at night or early in the morning until you both have agreed to be available to each other in case of emergency (such as if one of you is sick or has gotten some very bad news).
13. Know and honor each other's boundaries. People commonly set limits or boundaries around things like the amount of time and place of getting together, the kind of frequency of shared activities, phone call time limits—time of day, frequency and length, amount and kind of support given, connection with other family members, and the amount of physical touch. Say "no" to anything you don't want. You have the right to ask for what you need, want and deserve.

Problems In Relationships

If a difficult situation comes up in your relationship with a friend, you will both have to use your resourcefulness to solve the situation and keep the friendship strong. Some things you might try, depending on the situation, include:

- Talking with the other person by describing how you feel rather than making an assumption about how the other person feels;
- Working with your friend to develop a plan for resolving the situation that includes the steps each of you are going to take and when you are going to take them;
- Asking yourself what is really happening and deciding on solutions that will work for you;
- Being clear with yourself and your friends about your boundaries, saying "no" when necessary.

Ending a Friendship

You may want to end a relationship with another person if circumstances arise that you cannot tolerate or there are issues that cannot be resolved. Some good

reasons to end a friendship would be if the other person shares personal information about you with others, does all the talking and no listening, violates your boundaries, puts others or you down, teases, ridicules, "badmouths" friends and family, lies or is dishonest, wants you to be their only friend, wants you to spend all your time with them, wants to always know where you are and who you are with, doesn't want to be seen with you in public, is clingy or very needy, talks inappropriately about sex or personal matters, asks questions that make you feel uncomfortable, asks for risky favors, engages in illegal behavior or is physically, emotionally, or sexually abusive.

You may be tempted to pursue a relationship with someone even though they treat you or others badly. However, it is better not to have a certain friend than to have them treat you badly.

In Conclusion

The process of developing and keeping a circle of support goes on for as long as you live. I hope this column has been helpful to you in figuring out what you need to do next. Proceed slowly. Take small steps so you don't become overwhelmed. You may want to begin writing about your efforts in a journal. Later you can read about your progress and honor yourself for your efforts. You may want to refer to my new book, *The Loneliness Workbook: A Guide to Developing and Maintaining Lasting Connections* (Copeland, M.E. New Harbinger Publications. Oakland, CA, 2000).

CRISIS PLANNING*

I feel very strongly that anyone who has ever experienced psychiatric symptoms needs to develop for themselves, while they are well, a crisis plan such as the one that follows. This plan allows those of us who experience psychiatric symptoms to maintain some degree of control over our lives, even when it feels like everything is out of control.

Developing such a plan takes time—don't expect to do it in one sitting. Work on it with family members or friends, your counselor, case manager or psychiatrist—whoever feels comfortable to you.

The hardest part for me was uncovering those symptoms that indicate I need others to take over for me. It brought up memories of very hard times in the past. I did it very slowly with lots of support.

Once you have completed the plan, keep a copy for yourself, and give copies to all your supporters.

Update it whenever you need to.

CRISIS PLAN

When I am feeling well, I am (describe yourself when you are feeling well):

_____

_____

_____

The following symptoms indicate that I am no longer able to make decisions for myself, that I am no longer able to be responsible for myself or to make appropriate decisions:

_____

_____

_____

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When I clearly have some of the above symptoms, I want the following people to make decisions for me, see that I get appropriate treatment and to give me care and support:

I do not want the following people involved in any way in my care or treatment. List names and (optionally) why you do not want them involved:

Preferred medications and why:

Acceptable medications and why:

Unacceptable medications and why:

Acceptable treatments and why:

Unacceptable treatments and why:

Preferred treatment facilities and why:

Unacceptable treatment facilities and why:

What I want from my supporters when I am experiencing these symptoms:

What I don't want from my supporters when I am experiencing these symptoms:

What I want my supporters to do if I'm a danger to myself or others:

Things I need others to do for me and who I want to do it:

How I want disagreements between my supporters settled:

Things I can do for myself:

I (give, do not give) permission for my supporters to talk with each other about my symptoms and to make plans on how to assist me.

Indicators that supporters no longer need to use this plan:

_____

_____

_____

I developed this document myself with the help and support of:

_____

_____

Signed: _____ Date: _____

Attorney: _____ Date: _____

Witness: _____ Date: _____

Witness: _____ Date: _____