# Helping Yourself Prevent Relapse

By Patricia L. Scheifler, MSW, PIP
Peter J. Weiden, MD, Editor-in-Chief
Marcy Portnoff Gever, RPh, MEd, Educational Editor



# Helping Yourself Prevent Relapse

#### About the Author

Patricia L. Scheifler, MSW, PIP, is Director of Partnership for Recovery. She specializes in helping mental health professionals develop and improve their treatment services for people who are recovering from serious mental illness. Ms. Scheifler lectures at national meetings and presents workshops on how to manage serious mental illnesses. Partnership for Recovery can be reached at (205) 933-0735.

#### Editor-in-Chief

**Peter J. Weiden**, MD, is Associate Professor of Clinical Psychiatry at Columbia University, and Director of the Neurobiologic Disorders Service at St. Luke's–Roosevelt Hospital in New York City. Dr. Weiden specializes in the public health aspects of medication treatment for people with schizophrenia.

### **Educational Editor**

Marcy Portnoff Gever, RPh, MEd, is Medical Manager at Hastings Outcomes Management in Pennington, NJ, where she oversees the development of patient-directed programs dedicated to optimizing treatment outcomes. Ms. Gever specializes in patient education and is a columnist and author of numerous publications.

### **Advisory Board**

#### Laurie M. Flynn

Executive Director, National Alliance for the Mentally III (NAMI)

#### Don Fowls, MD

Sr. Vice President, National Medical Director, Options, Norfolk, VA

#### William Knoedler, MD

Director of Outpatient Services, Mendota Mental Health Institute, and Unit Chief, PACT Program, Madison, WI

#### Kimberly Littrell, APRN, CS

President & CEO, Promedica, Inc., Tucker, GA

#### Margarita López

Team Leader, Center Park Team, Project Reach Out, New York, NY

#### Kim T. Mueser, PhD

Associate Professor, Psychiatry, Dartmouth Medical School

#### Henry A. Nasrallah, MD

Chairman, Department of Psychiatry, Professor of Psychiatry and Neurology, The Ohio State University College of Medicine

#### Patricia L. Scheifler, MSW, PIP

Director, Partnership for Recovery, Birmingham, AL

#### Peter J. Weiden, MD

Director, Neurobiologic Disorders Service, St. Luke's-Roosevelt Hospital, and Associate Professor of Clinical Psychiatry, Columbia University

## Contents

- 2 What Does "Relapse" Mean?
- 4 Reasons Why a Relapse Can Happen
- 5 Changes in Your Treatment Can Cause a Relapse
- 6 Not Taking Medicines the Right Way Increases the Risk of Relapse
- 7 Too Much Stress Can Lead to Relapse
- 11 Other Reasons for Relapse
- 13 Ways You Can Reduce the Risk of Relapse
- 15 Knowing Your Early Warning Symptoms
- 17 The Dangers of Ignoring Early Warning Symptoms
- 18 Five Steps to Managing a Relapse
- 22 Answers to Common Questions About Preventing Relapse
- 25 When You're Feeling Your Best!



# What Does "Relapse" Mean?

The word "relapse" means different things to different people. People who are recovering from a mental illness have described relapse in many ways:

- "Relapse is when I feel nervous or afraid and I don't know why."
- "I have trouble sleeping, and the voices get louder."
- "My symptoms start coming back."
- "I feel like I'm sliding back down into the illness."
- "I feel like people are talking about me or watching me."

For most people, "relapse" means they're getting sick—their old symptoms are returning or their regular symptoms are getting worse. What does "relapse" mean to you?







## Relapse Can Often Be Prevented

Everyone's symptoms are different, so you might describe "relapse" a different way than someone else. But many people who start to relapse become very ill within a few days or weeks. They cannot overcome their symptoms on their own. And they may need to go to the hospital if their symptoms become dangerous or out of control.

This doesn't have to happen to *you*. Sometimes, relapse *can* be prevented. This book was written to show you how *you* can reduce your chances of having a relapse, so you can get on with other things in your life.





# Reasons Why a Relapse Can Happen

There are many reasons why people who have recovered from an illness may have a relapse:



- Their medicine may not be working well
- They may not be taking their medicine the right way
- They may be under more stress than usual
- They may not be getting enough rest
- They may have started another medicine for a different health problem (like a cold or muscle strain)
- They may have started drinking alcohol or using street drugs

## Overcoming Your Relapse Symptoms Before They Overcome You

When you're feeling well, your brain chemistry is relatively in balance. Any of the reasons mentioned above can upset this balance and cause your symptoms to return. Be alert to your symptoms—they can be a signal that a relapse is about to occur.

If you notice that your symptoms are starting to come back, tell your doctor or case manager right away. It's better to overcome your relapse symptoms before you get too sick and have to be hospitalized.

The next few pages focus on some of these causes and what you can do to overcome them.



# Changes in Your Treatment Can Cause a Relapse



A relapse can happen when you switch medicines or change the way you take your medicine. Your medicine plays an important role in adjusting a chemical imbalance in the brain that may be causing your symptoms. Any change in your treatment can change the balance of your brain chemistry—which can lead to relapse. There are many reasons. For example:



- Your doctor changes your medicine to a different medicine
- Your doctor tells you to take less of your medicine
- Your doctor adds another medicine to your treatment
- You start taking an over-the-counter medicine
- You miss doses of your medicine
- You stop taking your medicine

The best way to keep your symptoms under control is to work with your doctor to find the medicine and dosage that's right for you—then make the commitment to take your medicine the right way, every day.





# Not Taking Medicines the Right Way Increases the Risk of Relapse

## Some People May Not Understand the Way Their Medicine Works

They may say they can't "feel" the medicine working. They're right! Unlike pain medicines or cough medicines, you probably can't feel the way your medicine is helping to keep your symptoms under control. That's because the medicine works slowly. You probably can't see the difference from day to day.

## Some People Are Bothered by Side Effects



If you're being bothered by *side effects* (unwanted effects) from your medicine, tell your doctor. Your doctor may be able to help by adjusting your dosage. Or sometimes your doctor might give you an additional medicine to help your side effects. Don't make changes to your medicine on your own. Talk to your doctor if you have any ideas on how you would like to change your medicine or dosage—only your doctor is trained to work with you to find the medicine and dosage that's right for you.

# Many People Don't Know That Other Drugs or Alcohol Might Interfere



Other drugs, even mild ones that you can buy in the supermarket, might change your brain chemistry. If you need to take a medicine for a different health problem, ask your doctor which one is okay to take. Too much caffeine (found in coffee, colas, chocolate, and some medicines) as well as nicotine might also cause problems. Find out from your doctor how much caffeine (if any) you can have.

Alcohol and street drugs can cause problems too. They can throw your brain chemistry out of balance, even if you only use them once. Stay away from alcohol and street drugs, even if you're feeling all right.

Prevent Relapse—Keep Your Symptoms Under Control!

Taking your medicine the right way every day, and avoiding other drugs, will help keep your symptoms under control.



# Too Much Stress Can Lead to Relapse

There are two types of stress—the good kind (when you're happy and excited about something) and the bad kind (when something bad has happened). Both types of stress can upset the balance of your brain chemistry and cause relapse.

#### **Good Stress**

You may never have heard of good stress. Many people haven't! Good stress happens when you make a change in your life that you want to make. You might feel really excited about it. You might even have trouble sleeping a few nights before the change takes place. Here are some examples of things that can cause good stress:

- Getting out of the hospital
- Completing a treatment program
- Moving out on your own
- Going back to school
- Getting a job or changing jobs
- Being involved in a close relationship



vitat kilius of good stress have you experienced?						



## Keep Your Stress Level Low—Make Only One Change at a Time

Making too many changes at the same time might cause a lot of stress. And too much stress—even good stress—can sometimes lead to a relapse. If you plan to move, start a new class, or start a new job, talk it over with your doctor, case manager, or other member of your treatment team. New situations can be stressful and sometimes overwhelming. It's best for some people to try to make only one change at a time.

## Changes You'd Like to Make in the Future

List all of the changes you would like to plan for the future. Which change would you like to make first? Second? Third? Number them in order.





## Team Solutions | Workbook 7 Helping Yourself Prevent Relapse

### **Bad Stress**

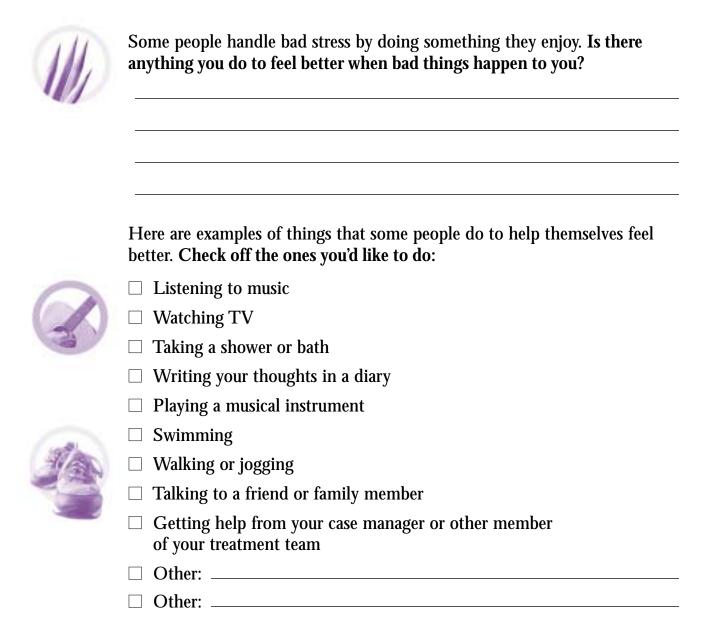
This is the kind of stress we usually think of when someone says they're under a lot of stress. Some things that can cause bad stress are:

- Having an argument with someone
- Having problems at a job
- Breaking up with someone or losing a friend
- Not having enough money
- Not liking where you live
- Being mistreated by others



What types of bad stress have you experienced?						



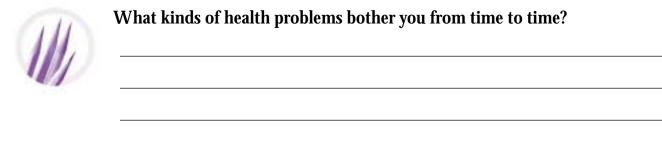




## Other Reasons for Relapse

#### Health Problems

You might notice that the symptoms of your mental illness get worse when you are sick with some other health problem. A toothache, the flu, or even a cold can add bad stress to your body. It's especially important to rest during this time so you can get better. If your symptoms begin to really bother you, call your doctor or case manager.



## You May Have a Symptom Cycle

Some people notice that their symptoms go away for a while, then come back, then go away for a while, then come back. This happens over and over for no real reason. People who have this problem may have their own "symptom cycle"—their symptoms appear and disappear in a pattern or cycle that repeats itself.



	Not everyone has a symptom cycle. The only way to find out if you have a symptom cycle is to record your symptoms every day for several months. Then you'll be able to see if there's a pattern. If there is a pattern, you and your doctor may be able to think of ways to manage your symptoms during the times they get worse.
111	Do you think you may have a symptom cycle?
101	□ Yes □ No □ Unsure
	Explain why:
	Would you like to find out if you have a symptom cycle? If so, start recording your symptoms on a calendar every day. Ask your case manager or other member of your treatment team to help you get started.
What's Yo	our Opinion?
11/1	Can you think of other things that could cause a relapse?  If so, what are they?
	What can you do to prevent these things from causing a relapse?



# Ways You Can Reduce the Risk of Relapse

The best way to reduce your chances of having a relapse is to take good care of yourself and watch your symptoms every week.

## Taking Care of Yourself

There are many things you can do to keep yourself feeling well. Here are tips from other people who say they're feeling better:



- "I go to sleep and wake up the same time every day."
- "I take a walk almost every day."
- "I feel better when I eat at least two or three meals every day."
- "I now know I have to keep taking my medicine every day things got really bad when I stopped it the last time."
- "If I feel really upset, I listen to music."
- "I stay away from my friends who like to drink—I can really get into it when I'm with them."
- "I met a friend with the same problem that I have, and we talk to each other every day."





## Watching Your Symptoms Every Day

You may have symptoms that have improved but haven't disappeared completely yet, even when you've taken your medicine every day. They are your "residual symptoms." They don't get better or worse—they seem to stay the same for a while.

To avoid relapse, what symptoms should you be watching for? Watch for residual symptoms that get worse or new symptoms that suddenly appear. These symptoms are your "early warning symptoms." They warn you that a relapse is starting.

"Early warning symptoms" can be described as:

- Changes you notice when you first start getting sick again.
- Symptoms that come back at the very beginning of a relapse.
- Strange things you experience when you start to get sick again.
- Changes in your behavior that other people notice when you start to relapse.





# **Knowing Your Early Warning Symptoms**

It's very important to know your early warning symptoms. Once you can recognize them, you may be able to take action to stop a relapse.

People who start to relapse say they experience certain changes. There are usually one or more early warning symptoms. Think back to when you first noticed any new symptoms. Check off the ones you've experienced:



$oldsymbol{ol}}}}}}}}} $			1 started	naving	trouble	sieepi	ıng at	mignt.
--	--	--	-----------	--------	---------	--------	--------	--------

- ☐ I couldn't concentrate or keep my mind on things like I could before.
- ☐ I was laughing one minute, then crying the next.
- $\square$  I forgot things more often than usual.
- ☐ I couldn't think as clearly as usual.
- ☐ My mind started "racing"—ideas started coming faster than usual.
- ☐ I started hearing voices.
- ☐ I felt afraid of people, places, or things that I used to feel comfortable with.
- ☐ I felt angry and got into lots of arguments.
- ☐ People said I was talking or acting strangely.
- ☐ I started feeling nervous or worried all the time.
- ☐ I thought people were talking about me or laughing at me.
- ☐ I started opening charge accounts and spending lots of money.





1	Z	1
K	3	B)
1	-	9

What other types of early warning symptoms did you have?						

Watching for early warning symptoms is the only way you can catch a relapse before it catches you! One way to keep track of your early warning symptoms is to write them on a calendar or journal on the right date. Also write down if the symptom has gotten worse since the last time you checked. That way, you can tell your doctor when your symptoms first started bothering you and if they've gotten worse over time.





# The Dangers of Ignoring Early Warning Symptoms

Sometimes people want to believe that there's nothing wrong, even when they're starting to see early warning symptoms of relapse. There are many reasons why people do this. Here is what they have said:

- "I just hoped it would go away."
- "I didn't want to have to go to the hospital again."
- "I didn't want to get sick again."
- "I didn't want my family to know I was getting sick again."
- "I didn't want to believe it was happening to me all over again."

You also might feel this way sometimes. But instead of ignoring your early warning symptoms, you could try to do some things to stop the relapse.

### Which Path Will You Choose?

## **Ignore your symptoms:**

- Symptoms don't go away.
- Symptoms get worse; new ones appear.
- Your symptoms start to control you.
- You have to go to the hospital.

## Take action to stop relapse:

- You start working toward feeling better sooner.
- You have a better chance to avoid hitting bottom.
- You'll be less likely to end up in the hospital.
- You can be more in control of yourself and your life.



# Five Steps to Managing a Relapse

Stopping a relapse may not be as hard as you think, if you follow these five steps:

- 1. Know the early warning symptoms you usually get.
- 2. Watch your symptoms every week. Notice if they get worse or if new ones appear.



- 3. Recognize that you're starting to relapse.
- 4. Call your case manager, doctor, nurse, or therapist. Tell them you're starting to relapse.
- 5. Take action to stop the relapse.

To help yourself get comfortable with these five steps, complete the answers to the questions on the next few pages. This information will help you prevent a relapse and tell you what to do if a relapse starts to happen.





STEP 1. Know yo	ur early warning symptoms.  What early warning symptoms will you be watching for?
	of your symptoms. Notice if they get worse or if new ear. Look for early warning symptoms.  What symptoms usually get worse?
	What kinds of new symptoms usually appear?



STEP 3. Recogniz	te that you're starting to relapse.  Why is it best not to ignore your early warning symptoms?
•	r case manager, doctor, nurse, or therapist. you're starting to relapse. Who will you call?
	Name: Phone number:
	What will you say?



## STEP 5.

Take action to stop the relapse.



Let your doctor, nurse, case manager, or therapist help you plan what to do to stop the relapse. Write down what you will do if you think a relapse is starting.

I plan to:				



# Answers to Common Questions About Preventing Relapse

You may have a few personal questions about your own risk for relapse. This is the time to ask all of your questions. We've provided a few of the questions often asked by clients and the answers:



**Question:** If I stopped taking my medicine and I feel a relapse coming on, is it okay to start taking my medicine again?



Answer: It depends on the type of medicine you were taking and how long ago you stopped it. Some medicines have to be restarted at a low dose. It's best to talk to your doctor about starting it again.



Question: Sometimes I like to drink a few beers with my friends. I heard you shouldn't mix medicines and alcohol, so should I stop taking my medicine when I plan to go drinking?



Answer: As a general rule, you should *always* take your medicine. Skipping even one dose can get your brain chemistry out of balance. It's best to avoid alcohol, but if you're really set on drinking with your friends, talk to your doctor about it. Only your doctor can tell you if it's safe to have a beer with the type of medicine you're taking.







Question: Can exercise cause a relapse?



Answer: Exercising is a great idea and can help prevent relapse. But don't overdo it! If you're talking about aerobic exercise (such as jogging) or working out with weights, it's a good idea to have your doctor check you before you begin. Other types of exercise (such as walking, swimming, or bicycling) are also very helpful. People tend to feel better after doing these kinds of activities. A 20-minute walk is a good way to start!



**Question:** I have so much trouble remembering to take my medicine. Any suggestions?



Answer: There are several things you can do. Many people find it helpful to take their medicine at the same time every day. For example, some take their dose right after brushing their teeth or before going to bed. Others like to take it with breakfast. If you are using a calendar to record your symptoms, you may also want to use the calendar to keep track of the doses you've taken. After taking your medicine, put a check mark on that day.

Another helpful tip is to use a pillbox that holds a week's worth of medicine. Using a calendar or pillbox will help you remember if you've taken your medicine each day. If neither of these ideas work for you, you may want to ask a friend or family member to remind you to take your dose each day.



Your	Own	Questions
------	-----	-----------

Write down any other questions you have about preventing relapse. Ask your case manager, doctor, nurse, or therapist about your questions and write their answers below.

Q	Your question:
A	Answer:
Q	Your question:
A	Answer:



# When You're Feeling Your Best!

The times you're feeling well are the times you must be especially careful to do all you can to prevent relapse. People who are busy and don't have symptoms sometimes forget what it was like when they were ill. They may think they are cured and might stop taking their medicine. They may be less careful about avoiding alcohol or watching for early warning symptoms.

Think of your medicine and all the other relapse prevention tips in this book as an insurance policy—one that will help you get on with your life. Continue to take all the necessary steps to prevent a relapse, even if you've been feeling well for several years.

Millions of people take medicine for different kinds of health problems. Many have found that it's easier to *prevent* problems from an illness than to *recover* from it. Watching your stress level, taking your medicine, and being aware of your symptoms are the best things you can do to prevent relapse and get on with other things in your life.



