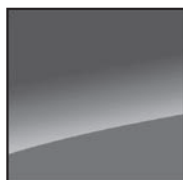


1

Beginning to Take Control of Your Pain



You may still have doubts about whether you can ever enjoy life again while you are in chronic pain. Nevertheless, let's at least explore how living a life of quality with chronic pain is possible. The keys are to take ownership of your pain (and this doesn't mean blaming yourself for it), determine exactly what your problems are as a result of the pain, and reassess your goals in the light of this information. This chapter gives you your first set of tools for beginning to take control of your pain: diary keeping and goal setting. To begin, look at the first of the three keys: accepting ownership of your pain.

Accepting Ownership of Your Pain

Your problem is that you are in pain and the pain won't go away. Defining the problem in this way is an important first step; before you can do anything about your pain, you need to acknowledge that it exists.

You may also feel inclined at this point to blame others for your pain. You may feel that your doctors have failed you by not finding and curing the source of the pain or at least by not making you feel better. You may believe that your loved ones are not doing anything to help you or are showing a lack of understanding or empathy for your problem. You may even feel that society is to blame for causing the situation that put you in pain in the first place or for not making it easier for you to seek help.

The fact that you may be sad, angry, or anxious about the disruption of your whole life as a result of the pain experience is both understandable and normal. Under these circumstances, it may be very tempting to feel that others are to blame for the pain and ought to be responsible for taking it away. Indeed, many people in pain put their whole lives on hold waiting for others—their physicians, their families, or society—to do just this. The difficulty is that wanting to give away both the pain and the responsibility for

copied with it only prolongs your feelings of powerlessness. If your pain is not going away anytime soon—and this is the very nature of chronic pain—then taking on responsibility for living with it begins to return control of your life to you. If you can adopt an attitude of “ownership” for the pain problem, then you have the potential to gain the upper hand over it. Although you may need assistance from your health care professional, your family, and society, it is ultimately your task, and yours alone, to untangle yourself from your pain web.

You may now be thinking, “Oh, great. So I’m responsible for my pain, huh? *I’m* to blame? That’s what everybody’s been saying—or at least hinting—all along. I feel bad and guilty enough as it is.” That is not what I mean here at all. As you probably already know, self-blame and guilt can be paralyzing emotions. They can make you feel so bad and worthless, there’s no point in doing anything at all. Accepting ownership of your pain, on the other hand, means acknowledging that you *are* a worthwhile person, that there *is* a point in doing something, and that you *do* have choices. It is very different from blaming yourself.

Chronic pain is complex, with many origins and treatments. It is grossly misunderstood. This book will provide you with the information you need to move forward. Even though your life is different from the way it was before the pain, you can change some of the consequences of having pain. You can learn to work with the consequences so that they cause you less distress. Your task is difficult—but not impossible.

Determining Exactly What Your Problems Are

Order and simplification are the first steps toward mastery of a subject—the actual enemy is the unknown.

—*Thomas Mann, The Magic Mountain (1924)*

The Importance of Tracking Your Pain Levels

One important way to gain understanding of your pain is to record it. This tracking process allows you to see what decreases or increases your pain—for instance, certain activities, weather, tension, and sleeplessness. Record your pain level three times a day, at regular times that are convenient for you. For example, you might write down your pain level when you wake up, after lunch, and then again at bedtime. Such consistency is important, because if you record your pain only when you are aware of it, you won’t necessarily notice when your pain level changes. Recording the pain at regular intervals will allow you to discover that there are patterns in your pain experience over time. Becoming aware of these patterns will help you determine what makes the pain better or worse, what helps and what hurts.

Many people are resistant at first to the idea of tracking their pain, and you may be one of them. Not only are you in pain to begin with, but it’s an additional hassle to have to record all this stuff—and three times a day! “Why do I have to do this? It’s not fair!” you may say. Perhaps the following story will help.

Paula was very angry at the thought of keeping track of her pain levels. Her back hurt and she already knew she was in pain. Why did she have to write it down three times a day, every day?

At first, Paula was so miserable that recording the pain just made her realize how bad she felt. Gradually, she realized how much she denied the pain in her back and how it prevented her from doing anything productive or pleasurable. Not only had she given up working outside the home, but she barely kept up with the household chores. Her house certainly wasn't as clean as it used to be. Even worse, she was irritable toward her husband and yelled at her children. She rarely saw her friends and really didn't care anymore about going out. Somehow this just wasn't the way Paula wanted to live.

Then Paula began to see how she pushed herself throughout the day and collapsed at night. Her back was stiff when she awoke, and the pain gradually increased during the day. What was causing the increase? Was it the fact that she "pushed, crashed, and burned" on a regular basis? Did this contribute to her feeling out of control? Would pacing her activities help? Slowly the answers became clear.

Over time, Paula saw that keeping track of her pain levels helped her learn more about the connection between her pain and her activities, what she did and how she did it. She was able to incorporate the skills she was learning for pain management into her daily routine and was eventually able to decrease the pain, bringing it more under her control.

If you don't think that recording your pain will be a chore, that's great. If you do, consider this: You have done your best in your current situation, and it still hasn't been effective in controlling your pain. Recording your pain levels can help you determine where you might be stuck and point you in the right direction. You can't count on remembering exactly what your pain feels like under all conditions over a long period of time. So give the recording method a shot—it just might work for you. Remember: *What you know, you can master.*

Keeping a Pain Diary

An effective way of tracking your pain is to keep the Pain Diary worksheet provided in Appendix F. There is a sample of a completed Pain Diary, along with a blank Pain Diary form that can be copied (or downloaded from _____).

In your Pain Diary it is important to keep track of both the physical (bodily) sensations of pain and any unpleasant emotions associated with the pain—the emotional response. "Physical sensation" refers to the aching, stabbing, burning, pounding, tightness, or other bodily symptoms you may feel. In the Pain Diary, "emotional response" refers to the unpleasant or negative emotions associated with your pain and is a measure

of suffering—for example, frustration, anxiety, anger, or sadness. Such unpleasant emotions are often associated with thinking such thoughts as “This [pain] will never go away,” “It’s not fair!,” “I’m useless,” and “My life is worthless.” These types of thoughts can make you feel worse and your pain even greater.

Note that the word “feel” can be used to describe both physical sensations and emotional reactions. This dual meaning can be confusing when you try to describe the pain experience to yourself and to the outside world. I began asking patients in pain to make the distinction between the two meanings years ago, at the last session of my very first pain group. The patients were talking about how great they felt and yet their “pain level” was only slightly lower than what they had recorded 10 weeks earlier. I was puzzled and I asked them to help me understand what had happened. They explained, “Oh, we still have pain [the physical sensation], but we feel so much better [the emotional response] about it. We aren’t helpless now, and we know what to do when our pain increases. We’re in control, not the pain!”

Most health care workers do not make this distinction and do not understand the dual meaning that pain can have. They make the mistake of using one scale, a single rating of pain, when they ask patients, “What pain level are you experiencing?” If you get asked this question, be sure to clarify what you mean. This greater clarity will assist you in getting the appropriate medicine or intervention at the correct dose or in a timely manner for your specific symptom.

The fact is that a lot more can be done about the emotional response to chronic pain than about the physical experience. And this can make you feel a whole lot better about dealing with your chronic pain, as it did with our patients. You can begin by getting in touch with how you experience your pain, both physically and emotionally. Become aware of the distinction between the two. You may find that at any one time you have more emotional than physical feelings related to your pain or just the opposite: more physical pain than emotional feelings. It will take some time and practice to see the difference, but it is worth the effort. Some of the exercises in the next few chapters will help you to separate these feelings.

I recommend that you continue to fill out the Pain Diary form for at least 3 months. You can stop once your pain levels appear stable and you are feeling better and in more control of your response to the pain. You can always start again if your pain worsens, a new symptom appears, or you want to track your response to a new treatment. Here are more detailed instructions for keeping your Pain Diary.

Instructions

1. Record your pain level on the Pain Diary form in Appendix F (see pp. 244–245) three times a day at regular intervals—for example, morning, noon, and bedtime. (There are smartphone apps as well that can assist with this; see Appendix E, “Electronic Resources.”)
2. Begin each recording by writing the date and time.

3. In the space under “Describe situation,” note what activities you were engaged in during the previous 4–6 hours. For example, were you watching TV, shopping, sitting at a computer, or cleaning the house or garage during that time?
4. Rate the intensity of your physical sensation (and its effect on your activities) by using the numbers in the following table. Write a one-word description of your physical sensation (for example, *burning, sharp, achy*). Separately, rate your emotional response using the numbers in the following table. Write a one-word description of your emotional response (for example, *angry, frustrated, sad*).

The numbers you give to your physical sensation and emotional response do not have to increase or decrease together. For example, you can have a high level of pain sensation and yet not necessarily suffer emotionally because of it. This will become more apparent as you proceed through the book and learn new pain management skills. Give ratings on a scale from 0 to 10 as follows:

Rating	Physical sensation/activities	Emotional/negative feelings response
0	No painful physical sensation; no alteration in activities	No negative emotional response
1–4	Low intensity of physical sensation; minimal effect on activities	Minimal/low level of negative emotions (frustrated, disappointed)
5–6	Moderate intensity of physical sensation associated with increased body tension; moderate restriction of activities	Moderate intensity of negative emotions (anxious, sad, irritable)
7–8	Significant pain sensation associated with difficulty moving; decreased activities	Significant negative emotions, making it hard to engage in activities (fearful, angry, depressed)
9–10	Severe pain sensation associated with inability to move; able to participate in only minimal activities; bedridden	Severe depression, anxiety, or despair associated with significant impairment in thinking

It may take several weeks to establish what the numbers mean for you. This is quite normal. Pain is a personal, individual experience, and you’ll only be rating your perceptions of that experience. (If you have difficulty, however, see the “Rating Your Pain” exercise under “Listening to Your Body” in Chapter 4.)

5. Record any medication or action you take to help alleviate the pain. For example, if you soak in a hot tub, go for a walk, stretch, or take two ibuprofen, record the fact.

6. At the end of each day, add the numbers from the three ratings for physical sensation together and average them by dividing the total by three. You will then have one daily physical sensation rating. Do the same for your ratings of emotional response. If visualizing information in graphic form is helpful, plot the numbers on a graph for the different times of day and for the daily averages. This may help you see the pain patterns more clearly over the weeks and months during which you develop your program of self-management.

The Pain Diary is intended for your benefit and self-exploration. You can change its format if that would be helpful. For example, you can record pain in two separate areas of the body, or you can record your emotional responses to life as well as your emotional responses to pain. The Pain Diary can also be an important source of information when you see your health care professional, particularly when the two of you are tracking symptom flare-ups or your response to treatment.

Noting Variations in Your Pain

If you find yourself rating your physical sensation with the same number three times a day, 7 days a week, examine your pain more closely. It is common for people in pain to think of their pain as overwhelming, unvarying, and unremitting. However, both physical sensation and emotional response vary; they rarely remain constant for days and weeks at a time. This natural variation is the result of your attention shifting from one thing to another. Mood, fatigue, muscle tension, and other factors also influence the pain experience from moment to moment. The brain is the final judge of sensory input and the center of emotional response. It tends to pay the most attention to changing levels of sensation or events. It quickly becomes bored with constant sounds, pain, and so forth, whether from outside or inside the body. As a result the pain and the awareness of pain will vary as well.

For example, if you go into a room with a fan humming overhead, you may be aware of the sound when you first enter; after a short period of time, you will “forget” the sound. If the fan shuts off, you may pay attention again, noticing the absence of the sound for a few seconds. Likewise, you may not be aware of the pressure of your back against a chair as you sit reading this, but now that I’ve pointed it out, you are suddenly aware of it. This awareness, too, will disappear after a few seconds as you read on.

You can make use of the brain’s short attention span for constant sensation; it is a way of altering the pain experience. Such techniques are discussed in later chapters.

What’s Next?

You are most likely going to feel worse for the next few weeks. You may say, “Oh, no! I thought this program was supposed to make me feel better, not worse.” Well, don’t panic just yet. This program begins by helping you identify what you have been experiencing, both physically and emotionally. If you begin to feel worse, it is not necessarily because the disease causing the pain is getting worse; it is more likely because you are bringing

your pain experience into consciousness. Bringing the pain to the front row of your attention can alter your sensitivity to it. Remember this for future reference: *Changing your awareness changes the pain experience.*

Many people use denial to cope with their pain. This may work for short-term problems. Long-term problems usually require conscious solutions or action. Awareness of your pain allows you to engage in activities in a way that will not make your pain worse. You will be asked to increase your awareness of your daily thoughts, experiences, and interactions throughout this program. You will learn how to distract yourself from the pain; however, this will be a conscious action, completely under your control, and free from any harmful side effects. It is a process that occurs in multiple steps and takes time. You are now just beginning the first step.

Setting Goals

People in pain often feel scattered, adrift, unfocused, and unsuccessful. Because pain restricts activities, it can become difficult to accomplish anything. No doubt, you find yourself unable to do all that you had hoped. When meaningful activity is taken away because of chronic pain, you suffer even more. Keeping a Pain Diary is one way to start focusing your life; it brings order to this “big unknown” (the pain) and helps you know how best to cope with it.

Another way is to set goals—a first step in slowly bringing order, success, and accomplishment back to your life. Setting goals will also help you commit to this program. But if you are not used to setting goals, it can seem tricky. The key is to set *achievable* goals—that is, goals you can accomplish. This is particularly important when you are learning how to live with your pain. You don’t need to feel like a failure any more than you perhaps already do. There are ways to set goals so that you cannot fail. When you take the goal-setting process slow and steady, each small success helps you reach higher.

Let’s start by choosing three goals you would like to achieve through working with the ideas and exercises in this book. The goals should be short-term ones that can be accomplished in 2 to 3 months. Use the following criteria to help develop achievable goals:

Goal-Setting Criteria

1. *A goal should be measurable.* How will you know when the goal has been accomplished?
2. *A goal should be realistic.* Is it possible to achieve, even in pain?
3. *A goal should be behavioral.* Does it involve specific actions or steps to take?
4. *A goal should be “I”-centered.* Are *you* the one engaging in the actions or behaviors to be measured?
5. *A goal should be desirable.* Do you want the results enough to put forth the effort?

Cindy's goal was to feel less stressed in 4 weeks. It sounded reasonable, but what exactly did it mean? Was the goal "feeling less stressed" measurable? What was "feeling stressed"? What did she mean by "less stressed"? What did she need to do to accomplish the goal? In other words, what specific steps did Cindy need to take? Her success would be left to chance if she didn't answer these questions. And leaving it to chance would not guarantee her success; it might even make it unlikely.

Cindy reworked her goal and decided that to her, "feeling stressed" meant feeling muscle tightness in the back of her neck. She wanted to be able to lessen this tension. If she could do that, maybe her headaches would be helped too. Now she could make a list of what she could do (*behaviors*) to accomplish her *measurable* and *desirable* goal—reduce tension in the neck and reduce the number of headaches. She would keep track of the number of headaches so she would know when her goal was accomplished.

Cindy decided that she would swim three times a week, take a stretch break from her work at the computer every hour for 60 seconds (see Chapter 4), and practice a relaxation response technique (see Chapter 3) once a day. She thus made her goal "*I*"-centered (she, not someone else, would be taking these steps), *behavioral* (there were specific, clear action steps to take), and *realistic* (these steps would be relatively easy for her to take).

After Cindy had worked toward her goal for a while, she could see for herself whether the tension in her neck had decreased and whether this was influencing her headaches. Her success was not left to chance but was the result of a conscious effort on her part.

Goal-Setting Exercise

Now write down three pain management goals that you would like to accomplish in the next 2 to 3 months. Make them achievable in each of the five ways described above. If you don't yet know what steps to take to accomplish the goals, leave those blank for now; come back to them after reading more of this book.

Let's use Cindy's goal as an example:

1. **Goal:** *Decrease tension in the back of the neck to decrease headaches.*

Steps to take to reach that goal:

- A. *Swim three times a week.*
- B. *Take frequent stretch breaks at the computer.*
- C. *Practice a relaxation technique once a day.*

Now it's your turn.

1. Goal:

Steps to take to reach that goal:

- A. _____
- B. _____
- C. _____

2. Goal:

Steps to take to reach that goal:

- A. _____
- B. _____
- C. _____

3. Goal:

Steps to take to reach that goal:

- A. _____
- B. _____
- C. _____

Setting goals now is a way of making a commitment to this self-management program. If you find yourself confused or resistant, ask yourself why. Have you been clear enough in defining what you want? Do you want something that you can't achieve at this time? Is there a part—even a small part—of what you want that is achievable? Don't be surprised if you find yourself feeling sad, angry, or frustrated with this exercise, particularly if there are things you wish to do but can't. It can be very rewarding to be flexible and identify other goals that are available to you in spite of the pain. Once again, you *do* have choices. Setting goals is a step toward identifying those options.

Congratulate yourself for having the courage and determination to begin this process. You have begun to gain control over your life!

Quick Skill

Overwhelmed by thinking 3 months into the future? How about a quick goal to begin? Is there something you are already doing and would like to do more? Maybe there are actions you've already taken and would like to acknowledge: for example, taking a hot shower in the morning or before bedtime, talking to a parent or a friend, filling the birdfeeder, or keeping track of the birds that come to it. So simple, no fuss.

Already doing it? Record it! Then see if you can expand the frequency or improve the task in some way using the five criteria mentioned on page 13.

Summary

- Taking ownership of your pain is the first step in gaining control over it.
- Recording your pain in the Pain Diary helps you track your physical pain sensation and your emotional response.
- Tracking your pain helps you see what increases or decreases it, and this information can tell you where your challenges are and help you see how you might solve them.
- Acknowledging your pain may make you feel worse—temporarily. However, you can learn to distract yourself consciously from pain.
- Setting achievable goals is important in bringing accomplishment back into your life.
- Achievable goals are measurable, realistic, behavioral, “I” centered, and desirable.

Exploration Tasks

1. When your pain gets worse, list the things that you do now to make it better:

2. Draw a picture of you and your pain. Use crayons or colored pencils. No black-and-white pictures, please! This artwork need not be displayed unless you want it to be, but it can be an important exercise to look at pain in a nonverbal way.

Use the space on the facing page to draw yourself and your pain:

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