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# **A Word Before You Get Started**

## ***How This Program Can Change Your Life***

If you feel pain much of the time, or if you have repeated episodes of severe pain over months or even years, you are very aware of how pain affects the quality of all parts of your life (physical, emotional, social, work, and household tasks). Only you know how your family and friends have been affected, the favorite activities you have given up, the social activities you've declined, and even the friends you have lost because of your pain-induced limitations. Perhaps you have tried medical treatments such as over-the-counter or prescription drugs, physical therapy, surgery, or complementary treatments such as chiropractic manipulations, dietary supplements, massage, or acupuncture.

Recently, the media has been filled with scary stories about one of the most commonly prescribed medications for pain—opioids. This group of drugs has been shown to be extremely beneficial for the short-term (acute) and chronic pain associated with cancer. In the past 40 years, opioids have also been prescribed for many chronic pain conditions that are not associated with cancer, in the hope that they would provide relief with limited negative effects. Only more recently have efforts been made to determine whether these drugs can be effective for controlling pain in the long term. The results have not been encouraging. Opioid drugs do not appear to demonstrate significant benefits when used on a long-term basis; moreover, they have been shown to have many negative physical and psychological effects including significant risks of dependence, misuse, abuse, and addiction (Ashburn & Fleisher, 2018; Buse et al., 2018). (Note that complete reference information for all materials cited in *The Pain Survival Guide* is included in the reference list at the end of the book.)

In addition, there is growing evidence that prescription opioids can lead to increased pain severity and, as a consequence, increased doses are needed

to maintain the modest benefits provided—creating a vicious circle. Faced with this evidence, providers are being encouraged and even required to reduce the number of conditions for which they prescribe opioids and to reduce the maximum doses substantially (Dowell, Haegerich, & Chou, 2016). If you have been prescribed opioids, you should discuss your continued use and the dose with your health care provider. As with all medications that you have been prescribed, you should not try to change your use on your own. Always discuss your wishes with your health care provider before making any changes.

Unfortunately, those who reduce their opioid prescriptions often do not have good options with which to replace them (Turk, Wilson, & Cahana, 2011). We provide in Appendix A an extensive list of commonly prescribed and recommended nonopioid treatments for chronic pain. However, we will be the first to acknowledge that none of the treatments in that list, taken alone or in combination, has been proven to completely eliminate pain.

When strong medications like opioids and all the other standard treatments lead to limited benefits (and sometimes substantial risks), your health care providers may tell you, “We’ve done all we can; you will just have to learn to live with it.” Such dismissive comments are very disheartening because you may feel you have few alternatives left. You do not want to “live with” your pain. You have been living with your pain for too long already. Rather, you want to live *without* it!

What if your practitioners told you that you can live with pain in a way that allows you to reclaim your life? That would be a different story. If they told you how you could bring quality and happiness back into your life by taking steps to take charge of your life and become resilient despite your pain, you might have realistic hope.

That is where our program begins—with the restoration of hope. By following a program that is clinically proven, you will, day by day and week by week, learn to self-manage your pain and reclaim your life. But success will depend on *you* and your efforts. This is quite a different approach from most of the treatments offered, in which you are passive and a health care provider does something to you. Each of the lessons in this book is backed by research and has been proven to help people, like you, with chronic health conditions to reduce their pain and other distressing symptoms and restore the quality of their lives.

In this book, we will help you and work with you to change your feelings of hopelessness, helplessness, and despair into realistic hope, empowerment, and resilience in the face of persistent pain and its many effects on your life. If your doctors and other health care providers have thrown up their hands and said that your case is “hopeless” or “treatment resistant” or that “you have to suffer with it,” we hope to help you prove them wrong. Most important, we will help you begin to live again, despite pain! This is an important point—living again *despite pain*. Although we believe that your active involvement with the strategies and techniques described throughout

this book can reduce your pain, making it more manageable, we are not suggesting that your involvement with this program will completely remove or cure your pain.

### **WHY NOT SEEK MORE MEDICAL TREATMENT?**

When you stand in line at the supermarket and see the headlines of magazines announcing remarkable new cures for arthritis, cancer, and other pain-inducing diseases, it's hard to turn away. But when you then consider these claims next to the more obviously sensational "news" about new sightings of dead people, alien abductions, and ways to lose 25 pounds in 5 days (with no effort, of course), you may reconsider the truth of such claims.

However, when you see (or when family or friends tell you about) mainstream media describing transplants of all kinds of complex organs and new heart disease surgeries and advertisements for new drugs and devices promising relief, you may more reasonably think, "Surely there must be a new treatment for my pain. Maybe one of these will work for me. Perhaps I should see the doctor again or visit an alternative medicine healer." This is understandable. We all want to believe that when we have a problem in our lives, there is someone out there who can fix it. No one suggests that there is no hope for your car when, after you have taken it in to the mechanic, it has problems again. People tell you to take the car back to the mechanic or get a new mechanic. But if your car is overheating again and again, if you use the wrong kind gas, if your driving habits are poor, you have to change something. It may not be the mechanic. Is it possible that you have to change something in your behavior or your lifestyle?

Similarly, pain can have a profound influence on your life. Just as you have to attend to your driving behaviors to keep your vehicle in good shape, you have to adapt to new circumstances when pain forces you to pay special attention to what your body needs. What to change and how to make needed changes are quests we undertake together.

If you have seen more than two doctors who are up-to-date on recent medical advances in pain, going to a third or fourth doctor is likely to cause more frustration and feelings of hopelessness.

Over the last decade, there have, indeed, been many significant advances in medicine for some medical conditions. However, despite these developments, there is currently no treatment that can eliminate *all* pain for *all* people *all* of the time. Even the most powerful treatments (namely, opioid drugs, anticonvulsant and antidepressant medications, and surgery) typically reduce pain by no more than 30%. And even reductions at this level are only seen in fewer than half of the people who receive them. Only rarely is pain completely eliminated by any of the currently available treatments. Right now, it makes more sense to become your own pain expert and begin to manage your pain and your life.

## **WHEN FRIENDS AND FAMILY DON'T HELP**

When you have chronic pain or frequently recurring bouts of pain, you may get the feeling that not only your doctor but also your family and closest friends do not realize what it feels like to have chronic pain 24 hours a day, 365 days a year, or to experience frequent devastating acute pain at unpredictable times and with no end in sight. Unlike when you have the flu and people can see and hear its effects, pain is maddeningly invisible to anyone else but the person afflicted. There is simply no pain thermometer that you can show to someone to prove how bad you feel, and words alone may fail to capture your experience.

Some family members or friends may subtly (or not so subtly) insinuate that you are exaggerating the extent and depth of your pain or your pain-induced limitations. The truly uninformed may suspect that you want to gain attention, elicit sympathy, avoid responsibilities, or receive disability payments. Such responses can contribute to feelings of undeserved shame. And they add to feelings of frustration, anger, and depression. It may be helpful to know that everyone feels bad when his or her concerns are not taken seriously, not just you.

## **SO WHAT SHOULD YOU DO NOW?**

Do you remember the *Peanuts* cartoon strip in which Charlie Brown is standing on the baseball mound talking to his friend Lucy? He tells her that he is not sure whether he should play baseball that day because his arm hurts, his stomach hurts, and his back hurts. Lucy advises, unsympathetically, "Play anyway! Don't let your body push you around!"

As you will see later in this book, it is not always wise to "play anyway" or play the same way. But Lucy's other point is totally in line with our thinking. As noted earlier, we do not promise or provide a miracle cure, but we will help you learn how not to "let your body push you around." We will be your advisers, teachers, coaches, and guides, and we will help you enlist people in your life to be on your team. This will ensure that you, not your pain, is in charge of your life.

Perhaps even those people whose remarks caused feelings of shame or anger in the past will be on your team once they see that you take your pain seriously enough to make self-managing it your priority. Perhaps when they see the efforts you are making, they will finally realize that your pain is real, after all, and ask how they might best be helpful in the journey. And, even if they don't, *you* will feel better. *You* will feel realistic hope, perhaps for the first time in years. *You* will take up some of your favorite activities again. And *you* will improve the quality of your life despite pain.

Are we exaggerating? Just giving you a pep talk? You will be the ultimate judge. But we promise that we are offering you a proven program that has

been used successfully with thousands of people, just like you, who also confront persistent pain. A great deal of research evidence exists to support our confidence in our approach to a wide variety of pain problems—back pain, fibromyalgia, chronic headache, arthritis, and many more. (In Appendix B we have listed other books you can consult for additional insight into the specific strategies, skills, and techniques detailed in each lesson.)

There are two things we must tell you, however. First, our program comes with a warning label. As with instructions on labels of antibiotic drugs, you must “take all the treatment in the book (bottle)” to obtain the full set of benefits. Second, although this program may appear relatively simple, simple does not necessarily mean easy. We know of no easy way to manage chronic pain. It does not exist. You will have to make pain self-management an important priority in your life. With regular and continued practice, what you learn over time will help you become more resilient and reclaim your life (but remember, despite your efforts, you should have realistic expectations about what you can achieve).

## **AN OVERVIEW OF THIS PROGRAM**

The program we have prepared consists of 10 related lessons. Each has a specific focus, but all are designed to help you gain control of your pain and your life. In fact, if these lessons are put into practice consistently, they can help you thrive despite pain.

In Lesson 1, you will learn about pain in general and about the incapacitating effects of chronic pain. You will learn that you are not alone. Surveys have shown that up to one third of the population of the United States and worldwide have some form of chronic or recurring pain problem. Most important, you will also learn some of the erroneous and harmful myths about pain. Believing these myths as if they were facts interferes with your ability to gain control over your pain. Knowledge is the true beginning of power.

In Lesson 2, you will learn to recognize the first important pain reducer—a pattern of optimal activity, rest, and pacing. Rather than the extremes of remaining immobile or pushing yourself too hard, you will learn how to find a proper balance between activity (exertion) and rest. You will learn the importance of pacing your activities to prevent increased pain while still being able to enjoy being active and accomplishing what you need to do and find important. Practicing will enable you to gradually increase your energy, activities, and conditioning without harming yourself or making your pain worse.

In Lesson 3, you will learn to recognize the value of the second key pain reducer—relaxation. This relaxation is not the kind in which you put your feet up and watch television in a mindless haze. You’re probably bored with that by now anyway, even if you may want to deny it at times. Instead, you will learn how you can create deep relaxation and achieve beneficial rest and hence enjoy many activities you may not have considered before.

In Lesson 4, we discuss the problems of chronic tiredness (fatigue) and disturbed sleep that many of our patients report experiencing. We share with you our best knowledge of how to reduce chronic fatigue and achieve a good night's rest. As you *consistently* practice Lessons 2, 3, and 4, you should notice a reduction in your experience of pain. Passively watching television will be even *more* boring because you will have better things to do with your time! Up to this point, you've been working alone with us, your guides.

In Lesson 5, you will learn how you can include other people in your life as teammates. We teach you to communicate with others in your life in such a way that they will support and encourage you. If they are stubborn, we help you find new people who can provide understanding and support and help you make the most of this program. You may not need a large team, but you do need at least one or two people to support you, encourage you, and appreciate your efforts. Understanding, acceptance, and support of others are proven pain reducers.

In Lesson 6, we focus on changing behavior—your own especially, but that of others around you as well—by applying the “laws of learning.” We will teach you a number of principles with which you can influence your behavior and (sometimes) that of others. You will learn how the behaviors and responses of others affect you, even without your being aware of this. You will also learn how to change certain aspects of your lifestyle that contribute to (note that we do not say *cause*) or worsen your pain.

In Lesson 7, we focus on how you think and feel when you experience pain and its effects on your life. We know you are not creating your pain by your thoughts and emotional reactions. But you can help manage your pain by changing how you think about and react to it. You will learn how you can influence and control your mental and emotional responses to the very real pain you are experiencing. You will be able to direct your thoughts and feelings so that they contribute to your sense of control and resourcefulness rather than to feelings of helplessness, hopelessness, and despair.

In Lesson 8, you will learn to regain self-confidence and to trust yourself again. Trusting yourself may seem odd. We usually think of trust as having to do with other people. However, people with chronic pain often lose trust in their bodies and hence themselves. If others are not supportive (and we include some health care practitioners here), you may lose trust in them as well. Trust, especially in yourself, and self-confidence are potent factors in managing pain. You will learn coping skills and problem-solving strategies to regain self-trust and self-confidence. These will allow you to manage your pain further.

In Lesson 9, you will learn more about the relation between your pain and how your daily habits may be influencing your awareness of and sensitivity to pain. You will also learn how your past experiences affect your relationship with pain now. You will learn to identify and change more things in your life that are contributing to the negative effects of your pain.

If you have reached Lesson 10 and have worked at each lesson diligently, you will have become more resilient in the face of pain and be much happier,

and you will have taken on many activities you never thought you would do again. However, it is just as important to learn to maintain these gains even when some level of pain continues or you have flare-ups of your pain.

In Lesson 10, we help you continue your self-management program, manage setbacks and relapses, and maintain the benefits you have achieved. As you learn that you can bounce back, you will be even more likely to confront and seek out new challenges. You will learn how to be resilient and to stay motivated for life!

In the lessons, we share several stories taken from our experience as clinicians. We have disguised the names of all individuals we discuss as examples and have taken care to change details of their cases so they cannot be identified.

We strongly encourage you to keep a diary or journal of your journey as you work through the lessons in this program. At the end of each lesson, we have included a set of questions for you to consider or exercises for you to complete. We have designed each “assignment” to help you practice specific skills and ways to manage your pain. You don’t have to do all of them. However, we encourage you to try at least a few. Some of our patients tell us they have gained the most from choosing the one question or exercise that they least wanted to answer or do. Participating in this way will help you relate the information in the lesson to your unique circumstances.

Most important are our suggestions for keeping track of your progress. The charts we introduce in Lessons 2 and 3 can be photocopied and should be kept in your journal or a notebook and referred to on an ongoing basis. They may also be downloaded and printed from <http://pubs.apa.org/books/supp/turk>. These records are critical because improvements can be so gradual that you may not know you are improving unless you have a record to look back on. Also, you may have heard that keeping a food diary has been shown to be a, if not *the* critical component in most weight-reduction programs. The same is true for reducing pain; keeping track of your efforts (not just successes) can help you get on track and stay on track over your journey.

At the end of the book, we also include a list of suggested additional reading, organized by lesson. These readings are optional, but they may help you when your motivation is lagging. Most of the books listed can be obtained from libraries or bookstores in your community or ordered online.

## **A NOTE OF ENCOURAGEMENT**

One of the many people who has consistently followed our pain management program wrote to us about her biggest achievement. She said,

Before the program, I got up with the thought “Heavens, another long, painful day. I wish it were evening again.” In the evening, in bed I thought, “Heavens, another long, painful night, I wish it were morning again.” In my darkest hours, I even thought that perhaps it would be better if I did not see the morning again. I knew that this was not living. I didn’t want to grow old like this. After consistently



following this program, I now sleep reasonably well, enjoy friends, family, and activities, and when I wake up, I look forward to the new day, even though I still have some pain.

Another reader of the first edition of this book said, "The desire to continue living and being able to feel a considerable degree of control over pain is the greatest achievement of my life, outside of raising my children."

One other reader who wrote to us noted, "I'm a new man now; I've regained my life." If you are ready to live again, and if you have opened this book, you've taken the first giant step on this journey we will take together. Let's get started.