Chronic Pain Won't Stop Me!

Tools to Make the Most Out of Life Despite Chronic Pain

Written by chronic pain patient **Tom Bowen** for other chronic pain patients

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Preface

Welcome! Inspired by my personal experience with chronic non-cancer pain, this book discusses the biopsychosocial approach I take to self-manage my pain with support from my healthcare team.

My chronic pain started in 2009 with nerve damage that arose following emergency groin surgery. Four years later, I fell and hit my head. That fall led to a constant headache, a whistling sound in my ear, back and hip pain, tingling and numbness in my hands and feet, electrical "shocks" in my legs, muscle soreness, and random pain and burning sensations throughout my body. My official diagnoses include fibromyalgia, costochondritis, sacroiliac joint dysfunction, tinnitus, irritable bowel syndrome, post-concussion syndrome, chronic headache, neuropathy, sleep apnea, chronic fatigue, anxiety, and depression.

I was fortunate to attend one of the few interdisciplinary, outpatient chronic pain programs in the United States — the Mayo Clinic Pain Rehabilitation Center in Rochester, MN. During the multiweek program, a team of nurses, doctors, pharmacists, psychologists, physical therapists, and occupational therapists helped me understand what was happening with me and discover what I needed to do to take back my life. The experience gave me hope and reduced my use of pain medications. My goal changed from ending the pain to living well in spite of it. I learned to accept the pain, adjust to it, and manage it.

My professional background is in advertising and marketing. You may have seen my articles in *Stat*, *National Pain Report*, or *Practical Pain Management*. I also oversee an internet resource center called **Chronic Pain Champions** (www.chronicpainchampions.com) and a Facebook support group called **Chronic Pain Champions — No Whining Allowed** (www.facebook.com/groups/painchampions). I encourage you to join us!

— Tom Bowen

Key Takeaways

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Below are some of the common themes you'll see inside this book. I call them the **pain truths**.

- The better we understand pain, the better equipped we are to manage it.
- All pain is real.
- Pain comes from the brain 100% of the time.
- Pain is an experience with biological, psychological, and social factors. It is not just a number on the pain scale.
- Chronic pain is an abnormal response that doesn't improve over time. It can arise long after an injury or illness heals.
- Chronic pain often has no known cause or cure.
- Once it becomes chronic, pain loses its warning function and becomes its own disease/condition.
- The longer we have pain, the less likely our symptoms are related to tissue damage or injury and the better our bodies become at turning up the pain volume.
- Hurt doesn't always mean harm.
- Stress and pain are closely related.
- Not all pain will go away, so it's important to accept it, adjust to it, and manage it.
- Once pain becomes chronic, the goal should be pain management to increase function and quality of life, not pain elimination.
- Pain can be modified and controlled by retraining an overprotective pain system.
- There are limits to biomedical treatment alone. We can't always be fixed with a pill, injection, or surgery.
- It's not enough to just treat the pain. We need to treat the whole person.
- Pain is inevitable, but suffering is optional. Pain is what we feel; it happens to us. Suffering is what we do with pain; we have a choice.
- What we think and feel about pain and how we react to it affects our pain experience.
- Chronic pain can be managed with the right combination of medical and non-medical treatments.
- We need to take active responsibility as patients for self-managing our pain with support from healthcare professionals.
- Pain can change. Recovery is possible.

> ***"It's possible to live a fulfilling life despite chronic pain."***

Understand Pain 2

The path to pain recovery starts with education. The more we know about pain, the better.

Pain is in the body and brain.

If anyone ever told you your pain is in your head, they were partially right. Pain is an output from the brain with biological and psychosocial components.

The International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience." It goes on to say that pain is subjective and can be experienced with or without actual or potential tissue damage.[1]

Much like an alarm, pain warns us of danger. It's part of our flight or fight response. It protects us. When our body senses danger, it sends a signal to the brain to figure out what we feel, how we react emotionally to the danger, and what we do to reduce the threat. The brain generates the pain. It's very much real.

ACUTE VS. CHRONIC PAIN

There are two types of pain: acute and chronic.

Acute pain, the body's normal response to tissue damage or injury, typically needs immediate medical attention. It is a symptom that tells us that something is wrong. The pain matches the damage, and treatment works. Acute pain is finite, generally lasting less than three months.

Chronic pain, on the other hand, is an abnormal response that doesn't improve over time. It can happen long after an injury or illness heals. It can be due to a degenerative disease like arthritis. It can be neurological. It can also have no known biological cause, as in the case of fibromyalgia and many common low-back pain conditions.

Once it becomes chronic, pain loses its warning function and becomes its own disease/condition. It's no longer useful. What you feel is what you feel, but the discomfort no longer indicates damage. The chronicity changes how the brain and central nervous system processes pain. Misfiring nerve signals continue to tell the body it hurts.

> ***"Pain is an experience, not just a number on a scale."***

We can become oversensitized to pain.

We can become overly sensitive to the pain. Just like an alarm that goes on and won't turn off. An overreaction or amplification, of sorts. It gets stuck on high alert — turning up the pain volume. Experts call this overreaction *centralized pain* or *central sensitization* — a phenomenon of the nervous system that is associated with the development, maintenance, and amplification of chronic pain.

We may feel pain when only lightly touched or bumped. The pain can even move away from the location of the original injury to different parts of the body. The characteristics of our pain — achiness or stabbing, tingling, or burning sensations, for example — can sometimes change.

Think about your body as a house and pain as its alarm system.

If the door of your house is broken, the house's alarm system will let you know that something is wrong. However, if the alarm goes off even after the door is repaired, there's something wrong with the alarm system, not the door.

Acute pain means there is a problem with the house. **Chronic pain** means there's a problem with the alarm system.

Central sensitization can happen in all chronic pain conditions, no matter the underlying cause. It has been tied to a variety of chronic pain conditions, including fibromyalgia, whiplash, shoulder pain, neuropathic pain, chronic fatigue syndrome, non-cardiac chest pain, irritable bowel syndrome, temporomandibular disorders, complex regional pain syndrome, low-back pain, osteoarthritis, pelvic pain, and headaches.

Think about people who feel pain radiating from a body part that's no longer there (also called "phantom pain"). No part should mean no pain, right? Yet the pain is still there because it is coming from the *brain*. The pain is very much real, despite the lack of tissue damage.

The good news is that central sensitization can be reversed by doing things that promote positive neuroplasticity like changing how we think about, react to, and manage pain. More about that later.

Warning: What your doctor or diagnostic test tells you may hurt you!

A guy in a white coat says your imaging test shows a degenerative disc in your back or a knee that is bone on bone. What if he tells you you're the worst case he's ever seen? What's your reaction? You may become anxious. You may become scared. You may even hurt just thinking about it.

Makes sense, huh? This is called the *nocebo effect*. The expectation of persistent or worsening pain can sometimes cause a diagnosis to create fear and do more harm than good.

You're not your x-ray.

MRIs and other imaging tests, including CT scans and x-rays, can add to this nocebo effect by medically legitimizing the pain. Testing can be misleading and open to interpretation — indicating that something is wrong even when there is no pain or by showing there's nothing wrong even when pain persists.

Research has found a poor correlation between the presence of imaging abnormalities and pain. In fact, pain and diagnostic imaging abnormalities are often part of the normal aging process.[2] Take back pain, for example. Although back pain is a common medical complaint, no specific cause is found in up to 85% of cases.[3]

It's no wonder that patients with chronic pain often overuse the medical system in their attempt to find a biological cause and solution to their pain.

That same overutilization can lead to more worry, more diagnostic testing, and more potentially unhelpful or even harmful treatment options.

There's no magical pill, procedure, or intervention.

Medical professionals don't have all the answers. In many cases, chronic pain doesn't have a clear physical cause. And when it does, the solutions may not be easy.

Unfortunately, there is no magical pill, procedure, or intervention that makes chronic pain disappear. While our current biomedical treatments are good, they provide minimal around-the-clock pain relief and can be accompanied by unacceptable side effects.

But that doesn't mean there's no hope. It's possible to turn down the pain volume by learning ways to manage it.

Opioids aren't the best or only answer.

Opioid medications mask pain and are best designed for the short-term treatment of acute pain, cancer pain, and pain at the end-of-life. They are not designed for long-term pain therapy. Although some chronic pain patients report short-term improvement with opioids, there are no conclusive studies showing the effectiveness of opioids for relieving pain, restoring function, or improving quality of life.[4,5]

Opioids also come with serious risks, including:

- **Side effects** — drowsiness, dizziness, nausea, vomiting, and constipation
- **Tolerance** — needing more of the drug over time to get the same benefit
- **Dependence** — not being able to stop the medicine without severe withdrawal symptoms
- **Hyperalgesia** — heightened sensitivity to pain caused by long-term opioid use
- **Addiction** — compulsively seeking out the drug
- **Other complications** — anxiety, depression, heart attacks, sexual problems, respiratory failure, and increased risk of accidents

The use of opioids should be a joint physician-patient decision based on risks and rewards. If used as therapy, opioids should be part of a comprehensive pain management plan. Any tapering should be done with careful oversight and with alternative treatments in mind. Chronic pain patients shouldn't be expected to abruptly stop opioid therapy.

Treat the person, not just the body.

We're more than our bodies. We aren't machines, yet we've been conditioned to treat chronic pain only from a biological/anatomical perspective. By focusing exclusively on the physical aspects of pain, we may miss two-thirds of its potential treatment.

Enter the biopsychosocial (BPS) model of pain.

This model of pain takes a holistic look at the experience of chronic pain. It not only addresses biological factors, it also considers psychological and social factors and the complex interactions between them that affect health and illness.

We aren't machines. We can't always be fixed.

BIOPSYCHOSOCIAL MODEL OF PAIN

Let's take closer look at the three factors in the biopsychosocial (BPS) model of pain.

Biological

The biological component of the pain experience refers to the physical body, genetic predispositions, and any correlating tissue damage, infections, and other physical stressors. It's what many people associate with pain. If we get hurt, we go to the doctor to get fixed.

To better understand this part of the BPS model and how it applies to you, ask yourself:

- How many doctors have you seen regarding your pain?
- How many x-rays and other tests have you undergone to diagnose your pain?
- How much time have you spent researching a cause and cure for your pain?
- How many pills, surgeries, and other interventions have you tried to relieve your pain?

- Has your doctor recommended you rest and protect your body?
- Have you lost muscle strength and endurance?
- Do you still hurt?

> ***Are you missing two-thirds of your potential pain treatment?***

Psychological

The psychological component of the pain experience refers to how you think about pain and your emotional and behavioral responses to it.

The more limited you are by your pain (e.g., being unable to get groceries or take a walk) and the more you think negatively about it, the more it can adversely impact your quality of life. It's no wonder that chronic pain patients are four times more likely to suffer from depression or anxiety than those who are pain-free.

To better understand this part of the BPS model and how it applies to you, ask yourself:

- How much time do you spend thinking about pain?
- Have you accepted the pain as your new normal, or are you still fighting it?
- Is it common for you to expect the worst (what pain doctors call "pain catastrophizing")?
- What verbal or nonverbal expressions do you show when you have pain? Do you moan, grimace, or rub the area that hurts?
- Has pain changed your mood? Have you become anxious or depressed? Do you complain or get "paingry"?
- Do you avoid activity in anticipation of pain or to prevent more damage to your body (what pain doctors call "fear avoidance")?
- Has the fear of pain caused you to become guarded, brace yourself, or change posture?

Social

The social component of the pain experience refers to your background, demographics, family attitudes, economic position, work environment, living situation, patient-provider interactions, and interpersonal relationships.

To better understand this part of the BPS model and how it applies to you, ask yourself:

- Is your access to pain care limited by insurance or geography?
- Do you have any cultural beliefs about pain that affect your care?

- What type of reactions do you get from the people in your life (e.g., family, friends, co-workers, medical team members)? Do they believe you? Do they get angry or frustrated? Or do they enable or coddle you?
- Has pain affected the activities you enjoy, such as exercise, hanging out with friends, doing hobbies, or going to movies?
- Have you become isolated, or have others isolated themselves from you?
- Do you have issues at work? Have you lost work or been forced to go on disability due to the pain?

Within the BPS model of pain, each of these three factors contributes to the pain experience. I'll use my fall as an example.

MY BPS EXAMPLE

Biologically

I initially developed a severe 24/7 headache.

Other symptoms and conditions followed over the next few years, including ringing in my ears, neuropathy, and random pains.

I became disabled and had trouble walking. My gait and speed were reminiscent of an elderly person, and I was only in my 50s.

Psychologically

I couldn't stop thinking about the pain. I became frustrated and angry.

I wanted to place blame for the fall and my pain.

I had trouble dealing with the stress at work.

I developed anxiety and became depressed.

Socially

I overutilized the medical system to find a cause and cure.

I tried pushing through the pain to keep up with work demands. My co-workers and supervisor questioned my work ethic and ability, which made me more frustrated.

Reactions from family and friends varied from supportive to protective.

PAIN EXPERIENCE

Chronic pain is a journey.

Below are seven common stages associated with the chronic pain journey. They may or may not happen in chronological order and can even arise at the same time.

1. **Shock**: You realize your pain has become chronic. A doctor may have told you could have pain for the rest of your life. You may even have been told you might not be able to continue to work.
2. **Denial**: You become defensive. You may question your doctor's skills and/or diagnosis. You may start bouncing between healthcare providers to find a cause or cure.
3. **Anger**: You look for something — or someone — to blame for the pain. You may get mad at a doctor or even at yourself.
4. **Fear and anxiety**: You become overly fearful and anxious about the pain. You grieve the past. You may wonder how your life is going to change and how you're going to live with your new reality. You can become anxious and stressed about being unable to meet your personal, professional, or financial obligations.
5. **Depression**: Your body reacts negatively to the stress. You can become sad and feel hopeless. You complain. You may sleep too much or not enough. You may even withdraw from other people and become isolated. Your pain can become amplified.
6. **Acceptance**: You recognize chronic pain as your new normal. The pain may never go away. Even though you accept the pain, you don't have to like it.
7. **Adaptation**: You learn to live despite the pain, using tools to help manage it.

Accept Pain

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"Acceptance doesn't mean resignation; it means understanding that something is what it is and that there's got to be a way through it."

— Michael J. Fox

The *struggle* with chronic pain is often worse than the pain itself. The struggle makes it easy to become preoccupied and distressed by your symptoms — and it can make you feel like a victim.

To minimize the struggle, it's helpful to come to terms with the pain as your "new normal." Make room for it instead of focusing on getting rid of it. Accept that pain is likely to be a permanent part of your life with no immediate cure.

Many patients find a sense of relief once they stop fighting the pain and no longer have the emotional and financial burdens associated with endless doctor visits, more tests, more medication, and more procedures. Acceptance can lead to less pain-related fear, less emotional distress (e.g., anxiety and depression), less physical disability, and even less pain.

YOU'RE IN THE DRIVER'S SEAT

Imagine being in a car with your chronic pain. Where is the pain?

Is pain behind the steering wheel — determining where you go and what you do? Or are you driving?

It's possible to change your pain experience and symptoms by taking away the control the pain has over you.

Take note of the pain, acknowledge it, and then let it go. The longer you hold onto the stress and worry associated with chronic pain, the heavier and more disabling it can become.

Accepting pain doesn't mean giving up hope or resigning yourself to a life of misery. Accepting pain is about grieving your losses, finding joy, and leading a fulfilling and functional life.

Hurt doesn't always mean harm.

Although all pain hurts, not all pain indicates damage. By being able to tell the difference between new acute pain and chronic pain, you can change how you react to chronic pain. Rather than feeling guarded and fearful, you'll feel calm and safe. You know what to expect from your pain by its very nature as chronic. It feels very different than twisting an ankle or getting stung by a bee. The pain doesn't match the damage.

Get off the pain merry-go-round.

No one likes pain, and we'll do almost anything to try and stop it. It's easy to jump on what I call the "pain merry-go-round." Visiting all types of healthcare providers. Going through x-rays, ultrasounds, MRIs, CT scans, and all sorts of other tests. Spending countless hours on the internet. Taking a concoction of opioid painkillers, non-opioid medicines, vitamins, and herbs. Getting injections. Even undergoing surgery.

Although some of these measures may help, others may not — and some may even make things worse. Meanwhile, they all cost time and money and delay chronic pain rehabilitation.

Grieve and move forward.

Chronic pain can change who you are and what you feel. Your time, job, money, relationships, self-image, independence, and sex life can all be affected. It's normal to be scared, angry, and depressed. You may even grieve your "old" life — a time when you were free of chronic pain. Despite these emotions, it's important to move forward by making room for the pain.

Pain may change your abilities. Don't let it change your desires.

Ability describes the skill necessary to do something. *Desire*, on the other hand, describes the *want* to do something. Focus on what you can and want to do — not on your limitations. Don't dwell on the past. Keep moving forward.

> ***"You aren't your pain. It doesn't define you."***

Don't be a victim.

Pain can make you feel powerless. In response, it's easy to play the victim by placing blame on the medical community or legal system, the drugs we take or don't take, our conditions, our social situations, ourselves, and even God. At times, it can feel like the entire world is against us.

HOW HEAVY IS THIS GLASS OF WATER?

The weight of the glass or the amount of water in it doesn't really matter. What matters is *how long* you hold the glass. The longer you hold it, the heavier it will feel. The same holds true for stress, worry, and pain.

It is far too tempting to dwell on all the ways we've been wronged. Anger and resentment, however, can prevent healing and negatively affect both our physical and mental health.

You can do nothing and hurt, or you can hurt and enjoy life.

Chronic pain can cause us to overprotect ourselves. Our natural reaction to pain is to avoid activities that worsen our discomfort or increase our perceived risk of further damage. When we become overly fearful and stop doing things in anticipation of pain, we can make things worse.

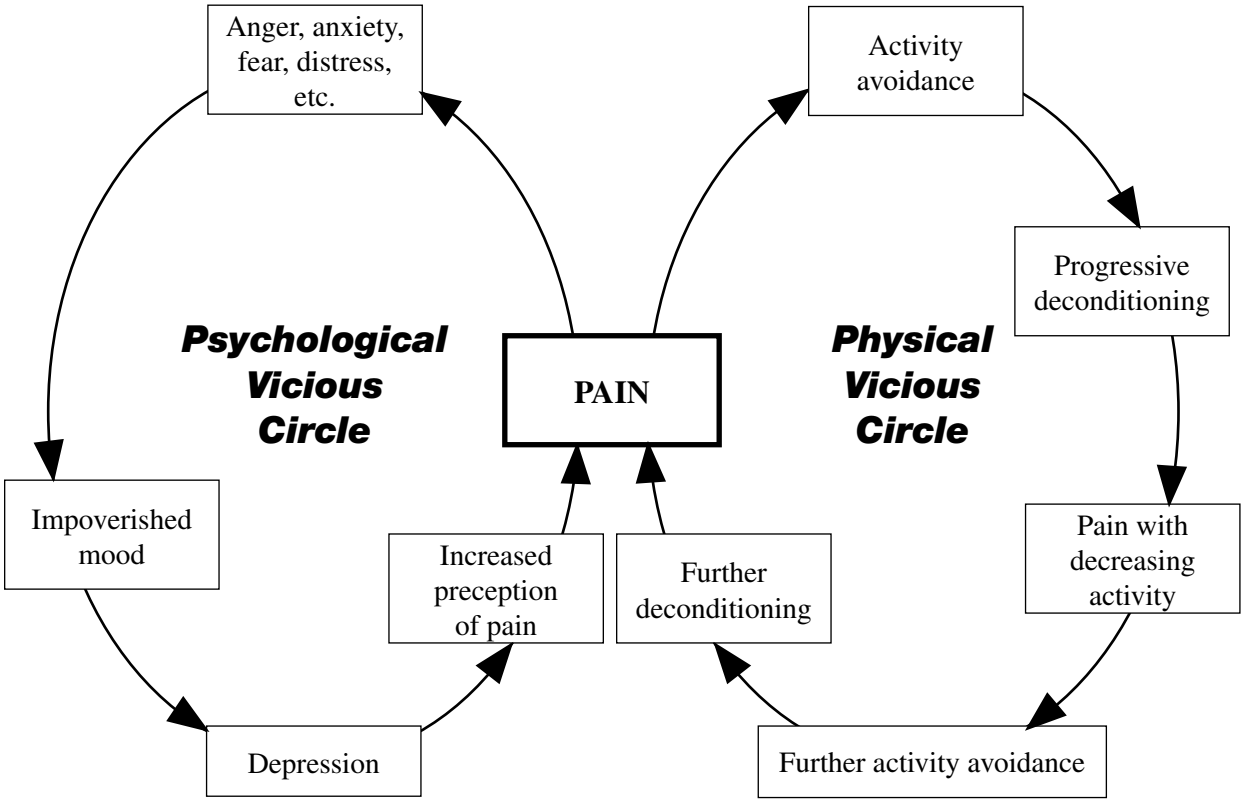
COSTS OF INACTIVITY

- Reduced pthysical fitness
- Weight gain and other health issues
- Less time with those we love
- More moodiness and depression
- Lower quality of life
- More pain

Inactivity reduces our functional ability and decreases our strength and stamina. It also prevents us from getting involved in the social, leisure, and work activities we enjoy.

The graphic below shows how the cycle of pain works. You'll find tips for becoming more active in the **Self-Manage Pain** section of this book.

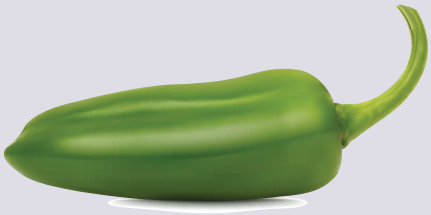
THE PAIN CYCLE



Adapted from Cooper, Booker and Spanswick, 2003

PAIN IS INEVITABLE. SUFFERING IS OPTIONAL.

Pain is part of the human condition, but it is possible to experience it without suffering. Take the act of eating a jalapeno, for example. It can be painful, but it doesn't cause true suffering. In fact, we may actually *enjoy* the pain because we like the taste of the pepper.



As humans, we can choose how we respond to pain. We can either choose to suffer or choose to live despite — and through — the pain. Research shows that the psychological and social distress associated with pain is often more important to the pain experience than the perceived severity of the pain itself.[6]

We don't go to the doctor just because we have a certain level of pain intensity that can be measured by a numbered pain scale. We go because the pain is affecting our quality of life.

Manage expectations.

It's important for patients, caregivers, and clinicians to manage their expectations about chronic pain treatment. Since chronic pain often has no cause or miracle cure, "zero pain" is an unrealistic goal. Focusing solely on pain reduction/elimination can make it harder to recover and get back to life. Expectations are more useful when they include improved functioning and better quality of life and not just a reduction in the pain itself.

Take responsibility.

Award-winning author Frank Sonnenberg once said, "It can't be done for you; it must be done by you." We must accept responsibility for making the most of our lives despite the pain. Our quality of life isn't the responsibility of the medical profession, the pharmaceutical industry, or our families and friends.

There is hope for improvement and a better life. You can stop the cycle of pain. **The power is yours.** You get to choose how you want to live in the present.

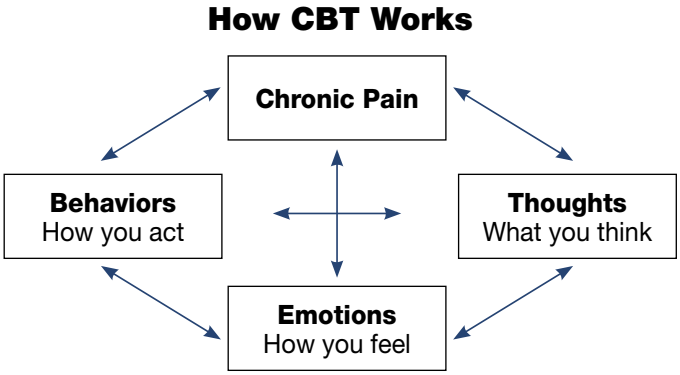
> *"You have to accept whatever comes, and the only important thing is that you meet it with the best you have to give."*
>
> —Eleanor Roosevelt

Change Pain

4

We can change pain and retrain our overprotective pain systems by changing how we think, feel, and behave using a form of biopsychosocial treatment called **Cognitive Behavioral Therapy (CBT)**. It reprograms our minds and bodies to help us feel safe and confident in our ability to manage pain and do the things we enjoy — improving the body's natural pain relief mechanisms, increasing function, and breaking the chronic pain cycle.

CBT is based on the core principles that our thoughts, emotions, and behaviors interact together with the pain; that we can become trapped in unhelpful thoughts, emotions, and behaviors; and that we can modify our thoughts, emotions, and behaviors to make our experience more manageable. There are several tools that can be used to help actively self-manage the pain (more details about those tools in the next chapter).



Change negative thinking.

Our thoughts can often be misleading and unhelpful, particularly when influenced by chronic pain. Do the statements below sound familiar? They're examples of negative thinking, also referred to as negative self-talk. This type of mindset increases our focus on the pain, reinforces it, and can actually worsen it — all while zapping our needed energy supply.

- ✓ I can't stop thinking about how much it hurts.
- ✓ There must be something wrong with me.
- ✓ My pain will never stop.
- ✓ I can't be happy until this pain goes away.
- ✓ I'm worthless.
- ✓ My life is ruined.
- ✓ There's no end in sight.
- ✓ So, what if I do more, I still hurt.

Negative thinking leads to rumination and brooding by fostering anger, worry, frustration, and hopelessness. It also causes what experts call "pain catastrophizing" — an exaggerated emotional response to actual or anticipated pain. Catastrophizing causes our minds to jump to the worst-case scenario. We become fearful of the pain, worrying about all the terrible things that might happen because of it.

Catastrophizing has been linked to higher levels of perceived pain, interference with daily activities, increased healthcare utilization, disability, depression, and changes in social support networks.[7]

You can improve your thinking in three steps using a technique called **cognitive restructuring**:

1. ***Identify negative thoughts***. Negative thoughts play off our emotions and can often recur for no real reason. They work *against* us instead of *for* us. Take note of them as they appear.
2. ***Challenge negative thoughts***. Are the thoughts you're having realistic? Are they factual? Do they help or hurt you? Are you catastrophizing or jumping to conclusions? Be kind and nonjudgmental. You aren't a bad person for thinking them.
3. ***Replace negative thoughts.*** Replace these thoughts with positive and more realistic ones like:
   - ✓ I'm working on getting better.
   - ✓ I can do this.
   - ✓ The pain is what it is.
   - ✓ I'm many things. Pain doesn't define me, and this won't last forever.

More replacement thoughts are featured on the next page.

Other helpful tips to shift negative thoughts include:[8]

- Avoid blowing things out of proportion.
- Look for the upside of downside situations.
- Focus on the solution instead of the problem.
- Pinpoint the opportunity in a challenge.
- Step back from roadblocks and brainstorm ways to overcome them.
- Hang out with positive people.

> *"**A positive attitude** enables a person to endure suffering and disappointment as well as enhance enjoyment and satisfaction. **A negative attitude** intensifies pain and deepens disappointments; it undermines and diminishes pleasure, happiness, and satisfaction; it may even lead to depression or physical illness."*
>
> —Viktor E. Frankl

REPLACEMENT THOUGHT EXAMPLES

Negative Thought	Replacement Thought
There must be something wrong with me because I hurt.	Hurt doesn't always mean harm. Pain is not an accurate measure of tissue damage.
Nothing else can help my pain.	There are no more treatments to hurt me. Even though I can't find a medical solution, there are coping skills I can use to manage the pain and quiet the noise.
I can't do anything anymore.	While I may not be able to do what I used to do, I can still be happy. I can live life well despite the pain. Challenge the assumption that you can't be productive. Think about what you can do and find ways to modify and moderate to participate more. [Information about modification and moderation are in the next chapter.]
It hurts when I do things.	I'd rather do things and hurt than not do things and still hurt. Despite my pain, I can still take care of my responsibilities. I'm safe to move; moving is good for me.
I'm in so much pain, I'm going to have to stay in bed until it improves.	Although my pain is strong today, it's a "false alarm." I can get up and take care of my basic needs, using my pain management tools to make use of this day as given to me.
I don't have the energy to do everything I want to do.	I can pace myself, do activities to recharge my energy, and set SMART goals to accomplish things.
If I do that workout/exercise, I'll have days of increased pain to make up for it.	I can learn a gentler way to exercise and keep track of which exercises don't cause a flare-up.
I can't manage the pain today.	Not every day is a bad day. I can get through this. Better times lie ahead.
I'll never get any sleep. I'll never make it through the day.	I'm still resting. No matter the amount of sleep I get, I can still function the next day. I'll sleep later.
My career is over. I'll never be "me" again.	I can still work and manage my pain. The stress and labor that were bringing me down are behind me. I have more free time to do so many things I could never get to before. A career title doesn't define me. There are other ways I can provide value.
My life is a mess.	I have it better than other people. Things could be worse.
I don't think I can go on like this.	I'm doing this every day. I'm a survivor, not a quitter. No matter what happens, I know I'll make it. No problem is hopeless.

Change negative behavior.

Pain behaviors are the things we say, think, and do to remind ourselves and others that we have symptoms. While these behaviors may be normal, they can become maladaptive, exaggerated, and anticipated responses. Particularly for patients with chronic pain, this can create a downward cycle of inactivity, disability, and pain.[9-11]

Pain behaviors put an undue focus on the pain and reinforce the pain circuits in our bodies. They tell your brain how to react the next time you have pain. Imagine a kid screaming for candy at the store. If you always buy the child candy when they scream, they'll continue to scream each time they're at the store because they associate the behavior with the reward/response. The behavior becomes learned.

Although it takes time and practice, controlling pain behaviors can help calm the body's alarm system and make our lives better.

HOW WE REINFORCE CHRONIC PAIN	
Vocalizations	Cry, gasp, groan, grunt, moan, say "ouch," swear (%$@#!), whimper
Facial Expressions	Distressed look, frown, grimace, squint, wrinkled face
Physical Expressions	Clinched fists, bracing, held breath, restlessness, rubbing, slow movement, tears, tense muscles, red or pale skin
Emotions	Anger, anxiousness, fear, irritability
Suffering Talk	Darn doctors can't solve my pain! I hurt…I am sick and tired of this… my day is ruined…not again…this is killing me…this is torture…what did I do to deserve this…why me…
Social Behavior	Unnecessarily relying on help, excessive sleep, frequent use of the healthcare system, taking medicine, guarding, limited social interaction, not getting out of house, poor grooming, withdrawing from activity

Don't share pain.

It's common for patients to talk about their pain levels and treatments with family and friends. Although talking about pain can help us validate our experience, it can actually worsen our symptoms by adding more attention to the pain.

You can't make positive steps in your life when surrounded by negativity. Stay away from people who only want to complain about pain, and avoid sharing your pain with others unless there is a positive goal associated with the conversation. Talk instead about things you enjoy and find meaningful. Fill your life with joy and hope!

It's natural for people to ask about your pain, but you have the power to change the discussion. Thank them for asking but explain that you'd rather focus on something else. Suggest a more life-affirming topic of conversation. Remember, pain doesn't define us. We're more than our pain.

I have seen way too much counterproductive pain talk on social media. That's why I started my own Facebook support group, where we try to limit complaining and negative talk. The group is called **Chronic Pain Champions — No Whining Allowed**. Join us!

Don't track pain.

It's common for chronic pain patients to keep a diary to record details about their pain, including symptoms, pain levels, daily activities, and treatments. In fact, there a variety of new digital apps designed to make this process faster and easier. But beware of giving your pain the extra attention. Chronicling your pain can actually amplify symptoms and slow recovery.[12]

You're not crazy. It's not all in your head.

Using a psychological tool like CBT isn't simply a case of "mind over matter." It doesn't mean the pain isn't real or is going to go away with wishful thinking. And it doesn't mean you have a psychological problem or that your symptoms are "all in your head." Nor does it mean you're weak — that you just need to suck it up, grin and bear it, live with the pain, and put on a happy face. It actually means you're taking control — using more of the available tools to manage your pain..

Make a commitment.

CBT works, but it takes work. It's a process, a tool. Don't expect instant results. To be effective, you need to commit to the process and believe in it. See a licensed CBT counselor, show up for therapy, and practice what you learn. Pain rehabilitation programs generally offer some type of psychological training, including CBT. **Learn more about pain rehabilitation in the next chapter.**

> ***"Instead of focusing on how stressed you are, remember how blessed you are."***

Where there is pain, there is gain.

Although the losses to chronic pain can be steep, we can have gains going through the process. We can gain new friendships. We can find new strengths by recognizing that we're the hero — we're stronger than our pain. And we can gain new purpose, just to name a few.

Self-Manage Pain 5

The pain may never go away. Just like rain, it can't be stopped. But if you have an umbrella, you can avoid getting soaked. No matter the amount of pain, CBT-based self-management tools can be used to help calm the mind and body, function more easily, and live life more fully. All it takes is time, patience, and practice.

Plan and prioritize.

By planning and prioritizing, you can reduce stress, lessen the risk of over-activity, and increase your chances of success. Set attainable goals and write them down. Describe the steps you're going to take to achieve them and set a timeline. Writing goals helps reinforce them. Plus, your notes can serve as a written reminder.

One of the tools we learned at the Mayo Pain Rehabilitation Center was **goal-setting**. We set goals each day. They didn't have to be massive, but they had to be **SMART**: **s**pecific, **m**easurable, **a**chievable, **r**elevant, and **t**ime-bound.

- **Specific** — What do you want to do? What actions will you take?
- **Measurable** — How will you track progress and know when you've reached the finish line?
- **Achievable** — Is it something you can do? Do you have the necessary skills and resources?
- **Relevant** — Why is it important to you?
- **Time-bound** — When do you want to accomplish it?

EXAMPLES OF SMART GOALS

- ✓ Increase my step count to 5,000 steps a day by the end of week.
- ✓ Do deep breathing for three minutes, three times each day for next week.
- ✓ Read three articles about CBT by the end of the week.
- ✓ Plan an in-person social event with friends and family this week.
- ✓ Lose 4 to 8 pounds of weight in the next 30 days.
- ✓ Volunteer 10 hours a week at the community center for the next month.

In addition to setting goals, schedule daily activities like stretching, hygiene, deep breathing or going for a walk. Like writing goals, scheduling helps keep you on track.

Physical activity, movement, and exercise

While it may seem counterintuitive, physical activity can both reduce pain and increase pain thresholds.[13,14] In addition, it also helps improve health, balance, and conditioning; manage weight; improve sleep; and increase flexibility.

Challenge any negative thoughts about being physical. You're probably already incorporating physical movement in your daily activities anyway. Getting the mail, shopping, and housekeeping all count. Exercising doesn't have to be daunting.

You may want to start with light, fun, and easy-to-do activities like stretching, yoga, tai chi, or going for a walk. If you have an activity tracker, set a goal for the number of steps you want to reach each day. You might even want to try pool therapy or strength training.

If unsure what to do, ask you healthcare providers about what exercises and activities are safe for you. Studies show that people with chronic muscle or joint pain who walk for exercise have less pain and better mobility than those who don't exercise.[15]

Don't get frustrated if you have difficulty or experience issues when you become more active. In particular, a temporary increase in muscle pain is normal when you start to use your body more. Activity-related pain doesn't equal activity-related tissue damage. Things will get easier as you build strength, flexibility, and endurance.

Bottom line: Do what you can do. Moderate and modify your activity, and be careful not to overdo it.

Talk to your doctor before beginning any exercise program. Your doctor and physical therapist can help determine the best plan for you.

> ***"Movement can make life better."***

Relax to relieve stress.

Like pain, stress is a normal physiological response that acts as a signal to protect us from danger. But when we become overwhelmed by pain and the pressures of normal daily life, stress overworks the body — putting it on high alert and making our symptoms worse. And when the pain increases, we become even more stressed. It's a vicious cycle.

To help activate your body's natural relaxation response, you can use these mind-body tools:

- **Deep breathing** (also called diaphragmatic breathing, abdominal breathing, and belly breathing — It's easy to learn and can be done anywhere.
- **Yoga** and **tai chi** — Movements can be modified, if needed, to accommodate individual needs (e.g., chair yoga or tai-chi chih [a simplified version of tai chi)]).
- **Meditation** — Requires you to redirect your attention.

- **Passive muscle relaxation** — Mentally relax your muscles from head to toe.
- **Progressive muscle relaxation** — Actively tense and relax your muscles from head to toe.

Guided versions of these tools are available online. You can find links in the Resources section of chronicpainchampions.com.

DEEP BREATHING IS EASY AS 1-2-3

1. Breathe in through your nose.
2. Breathe into your abdomen, feel your belly rise, then let air slowly fill your lungs.
3. Hold your breath before exhaling through your mouth or nose.

Do this for 5 minutes, two or three times a day or when you need to relax.

Moderate what you do.

People with chronic pain often do too much when they're having good days (boom!) and not enough (bust!) when they're having bad days. Moderation/pacing helps reduce the boom-or-bust cycle of overactivity/underactivity to improve overall function and reduce symptoms.

> ***"Calm the mind. Calm the body."***

Ways to pace activity include:

- Setting time limits
- Slowing down (start low, go slow)
- Breaking up tasks
- Taking frequent, short breaks — gradually increasing what you can do to build endurance
- Setting goals to gradually increase your level of activity

Be careful not to let pacing become an excuse for being inactive or avoiding pain. Doing so can add more focus to the pain, worsen symptoms, and reduce physical stamina. Remember, pain doesn't mean harm. It's the result of an overly protective system trying to defend itself.

Also, be careful to avoid using pacing to just push through the pain. Pacing is best used to gradually increase what we can do despite the pain. The difference is in the goal and execution. The emphasis should be increasing function and daily activity. The pain should lessen over time.

Modify what you do.

Why make things harder than they need to be? Techniques like breaking up activities and good body mechanics make things easier, not harder. This is especially true for activities you enjoyed before the pain. It's possible to find the joy again!

Try these:

- Turn instead of twist.
- Push instead of pull.
- Limit reaching.
- Kneel or squat instead of bending.

> ***Put pain in the background.***

An occupational therapist can help guide you through moderation and modification techniques, as well as other recommended health-management routines.

Distract yourself.

One of the easiest, most effective, and most recommended ways to manage pain is to change the way your brain perceives it by distracting yourself from your symptoms. By focusing on something else, you pay less attention to the pain — shifting it from the foreground to the background, thereby reducing the pain experience.

Ways to distract yourself include:

- **Laugh** — Laughter has been said to be the best medicine. It's hard to be stressed and upset when you're laughing or smiling. Watch a funny movie or TV show. Give yourself permission to be silly.
- **Listen to music** — Music has an analgesic effect that helps us feel better.
- **Talk with a friend** — A friendly face or voice can be calming. Call or visit a friend, but remember to limit the pain talk.
- **Enjoy nature** — Nature is beautiful and magical. Go for a walk. Watch the birds from a window. Go fishing. Spending time outdoors is therapeutic. If unable to go outdoors, watch a nature video/TV program.

- **Play** — Remember how you used to play as a child and how good it made you feel? Start a hobby. Engage a family member or friend in a board game. Color. Create art. Write in a journal. Make something crafty. Do a crossword puzzle. Play computer or virtual reality games.

Be mindful.

It's easy for our minds to wander and lose touch with the things we enjoy. Mindfulness redirects us from the wandering negative thoughts so we can enjoy the present with no judgment, rumination, or worry about the pain. It simply asks us to become aware of our senses and free our minds.

We can practice mindfulness when simply taking a deep breath by focusing on the breath itself, how we breathe, and what the air feels like coming in and out of our bodies. We can also practice mindfulness when listening or doing simple things like walking or playing with our pets.

Research has shown that mindfulness can improve disability, quality of life, self-efficacy, pain catastrophizing, and depression.[16]

Be kind to others and offer forgiveness.

Show compassion and dignity. Choose to be a role model instead of a victim. Forgiveness isn't just a nice thing to do. It doesn't mean forgetting. It isn't dependent on an apology. It neither excuses nor justifies past actions. It doesn't release any responsibility. Forgiveness is a gift that frees us from the burdens of resentment and negativity. It enables us to move forward.

Be grateful.

When times get tough, get grateful. Being grateful won't make pain disappear, but it can release suffering, change your perspective, and boost your mood.

Ways to practice gratefulness include:

- Say thank you.
- Make a gratitude list of what and whom you are thankful for.
- Start and end each day with a grateful thought.
- Write thank-you letters.

Which line are YOU in? Choose gratitude.

Be kind to yourself.

There is still a core "you" despite the pain. Sometimes we can be our own worst critic.

- Write down your positive qualities and accomplishments. What's good about you?
- Balance expectations.
- It's okay to not be perfect.
- Say "no" if you need to.
- Accept help.
- Forgive yourself.
- Eat healthy. Don't smoke or drink. A poor diet, nicotine, and alcohol can worsen the pain.
- Sleep better. (See tips below.)
- Talk with your loved ones about your needs and challenges without complaining. We don't want sympathy; we want understanding.
- Reward yourself and celebrate your successes, no matter how small.

> ***"Focus on what you have, not on what you've lost."***

Sleep Better. Feel Better.

Chronic pain can interrupt sleep, and poor sleep can worsen pain. Here are some tips for better sleep.

- Keep a regular sleep routine. Go to bed at the same time each each evening.
- Make the bedroom a sanctuary for only sleep and sex. No TV. No computer. No reading.
- Keep the bedroom dark, cool, and comfortable.
- No caffeine after noon.
- Minimize your use of nicotine, alcohol, and sleep medications.
- Avoid exercising late in the evening.
- Remove clocks from the room.
- No screen time (TV or computer) before bedtime.
- Do something relaxing like read a book (outside the bedroom) or bathe before bedtime.
- Limit daytime naps to 20–30 minutes.
- Don't lie in bed if you can't sleep. Go to another room and read or do something else to relax.

- Challenge negative thoughts.
- Don't worry about the quantity or quality of your sleep. Know that you can still function the next day no matter how much or how little sleep you get.

Prepare for a flare.

It will happen. You'll have one of those difficult days. Prepare for those days *now* by putting together a kit to help get you through the rough times. Inside this kit could be a letter reminding you to stay positive, a list of your best qualities and accomplishments, your favorite candy, music, photos, and whatever else provides short-term comfort.

Explore pain rehabilitation.

Talk to your doctor about the biopsychosocial model of pain rehabilitation. Pain rehabilitation goes beyond medicine and medical interventions by crossing into different disciplines. It doesn't just focus on removing the pain. It focuses on how we can play a role in our own pain management.

Pain rehabilitation has been proven to benefit patients while reducing costs and reliance on the medical system.[17–19] In addition to their general efficacy, interdisciplinary chronic pain rehabilitation programs can be effective for weaning patients off opioid therapy with long-term improvements in pain, mood, and function.[20] Having gone through the three-week outpatient Mayo Clinic Pain Rehabilitation program at the recommendation of both my family doctor and a general surgeon, I can personally attest to the value of a comprehensive interdisciplinary approach to pain rehabilitation.

Do I still have pain? Of course, I do. But I've learned to live well in spite of it. Read about my experience at Mayo Clinic in an article I wrote for *Practical Pain Management*. You'll find a link to the article in the Education section of chronicpainchampions.com. Links to select pain rehabilitation programs around the world are provided in the Resources section of chronicpainchampions.com. Local and regional programs may also be available.

Common Chronic Pain Rehabilitation Program Components WHAT TO EXPECT	
Medical management	To find the right combination of medicines and interventions and taper/stop any unnecessary treatments along with better monitoring of patients who are prescribed opioids
Pain education	To better understand what pain is, how to react to the pain, and make it easier to develop coping strategies
Lifestyle changes	To improve diet, sleep, etc.
Psychological therapy	To change self-limiting thoughts and provide coping skills
Physical therapy/exercise	To build strength, flexibility, and endurance
Occupational therapy	To modify and moderate daily activities
Relaxation training	To reduce stress on the mind and body
Family therapy	To teach loved ones how to help/not help those in pain

What changes are **YOU** ready to make?

Please visit chronicpainchampions.com to read my blog, access articles and videos about pain, join my Facebook support group, download self-management tools, and much more.

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Are you tired of fighting the pain? Champion it!

It's possible to live well despite the pain.

This book describes my experience as a chronic pain patient, my research, and the biopsychosocial approach I use to self-manage my symptoms based on what I learned during my treatment at the Mayo Clinic Pain Rehabilitation Center. The text provides a simple yet understandable explanation of pain, diffuses the fears that surround chronic pain, and provides tools to help patients relieve symptoms, reduce distress, and increase functioning.

I hope you find the book helpful.

chronicpainchampions.com