

Chronic Pain

WON'T

Stop Me!

**Tools to Make the Most of Life,
Despite Chronic Pain**

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

Version 4

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This book is for informational purposes only and should be used in conjunction with healthcare professionals. It's not meant to replace medical or professional advice.

Information provided in the book is based on the author's personal experience, beliefs, and research regarding non-cancer/end-of-life chronic pain. It's not a detailed plan for pain rehabilitation but is meant as a launching pad to start you on the next phase of your journey.

Consult a doctor or other healthcare professional before attempting treatment. Use of the information provided in the book is at your own risk.

The author makes no money from the publication of this book.

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I would like to thank my wife, Charlene, and my children, Marie, and Dennis, as well as the rest of my family, friends, and healthcare team for their support during my pain journey.

Thanks also to the Mayo Clinic Pain Rehabilitation Center for teaching me so much during the time I spent at your program. You changed my life.

And thanks to Dr. Eric Barlow and Dr. Bryan Hall for reviewing the first version of this book. I appreciate your support for me in my own pain journey as well as your support of my advocacy efforts.

A NOTE FROM THE AUTHOR

This book is my experience as a chronic non-cancer pain patient and the biopsychosocial approach I take to self-manage my pain with help from my healthcare team.

We're all different just like our pain. What works for me may not work for you. Hopefully, you can benefit from what I've learned to better control your pain and better your life. Recovery is possible!

My story

My chronic pain started in 2009 with nerve damage after 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 pain-related diagnoses include, fibromyalgia, costochondritis, sacroiliac joint dysfunction, tinnitus, IBS, post-concussion syndrome, chronic headache, neuropathy, sleep apnea, chronic fatigue, anxiety, and depression.

I was fortunate to attend one of the few multi-week interdisciplinary outpatient chronic pain programs in the United States for non-cancer/end-of-life pain – the **Mayo Clinic Pain Rehabilitation Center** in Rochester, MN. And not just once, but twice.

A team of nurses, doctors, pharmacists, psychologists, physical therapists, and occupational therapists at Mayo helped me understand what was happening with me and discover what I needed to do to take back my life. The program gave me hope. My goal changed from ending the pain to living despite it.

I learned to ***accept*** the pain, ***adjust*** to it, and ***manage it***.

Yes, I still hurt. I choose to not focus on the moderate to severe pain I have each day – which is, of course, easier said than done. I will not let the pain win.

My background

I'm not a trained medical professional. REPEAT... I'm not a trained medical professional.

My 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/blog **Chronic Pain Champions** and a Facebook support group **Chronic Pain Champions – No Whining Allowed**. Visit us and follow us!

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1 KEY TAKE-AWAYS

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, not just a number on the pain scale.
- Chronic pain is an abnormal response and doesn't improve over time. It can happen 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 it is related to tissue damage or injury and the better our bodies become at creating it.
- Stress and pain are closely related.
- Not all pain will go away – 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.
- Hurt doesn't always mean harm.
- Pain can be modified and controlled.
- There are limits to biomedical treatment alone. We can't always be fixed with a pill, injection, or surgery.
- Just treating the pain is not enough, we need to treat the whole person.
- What we think and feel about pain, as well as how we react to pain, 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 our healthcare professionals.

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

2 UNDERSTAND PAIN

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.

There are both biological and psychosocial components to pain.

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



Pain warns us of danger. It alerts us like an alarm. 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 danger. The brain generates the pain. It’s very much real.

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

Two types of pain

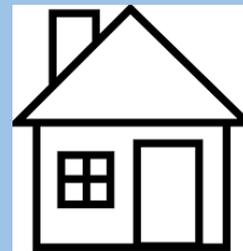
There are two types of pain: acute and chronic.

Acute pain is the body's normal response to tissue damage or injury and typically needs immediate medical attention – a symptom telling us something is wrong. It is useful – serving a biological purpose. And it is finite – healing and generally lasting less than three months.

Chronic pain is an abnormal response and 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 is no longer an indicator of damage. The chronicity changes how the brain and central nervous system processes pain – misfiring nerve signals and continuing to tell the body it hurts.

The house metaphor on this page helps explain the difference between acute and chronic pain.



Think about your body as a house and pain as the alarm system for the house

If the door of your house is broken, the house's alarm system will go off to let you know something is wrong with the house.

If the alarm is going 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.

We can become over-sensitized

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. And it is associated with the development, maintenance, and amplification of chronic pain.

We may feel it when only lightly touched or bumped. The pain can move around to different areas of the body other than the spot of the original injury. It can even change the type of feeling we may have like achiness, stabbing, tingling, or burning, for example.

And it can happen in all chronic pain conditions, no matter the underlying cause. Central sensitization 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 headache.

Think about people who feel pain coming from a body part that's no longer there (also called phantom pain). No part should mean no pain. Right? Yet, they still feel pain. The pain is coming from the brain. The pain is very much real, despite any tissue damage.

The good news:

Central sensitization can be reversed by doing things that promote positive neuroplasticity like changing how we think about pain, react to pain, and manage pain. More about that later in this book.

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.



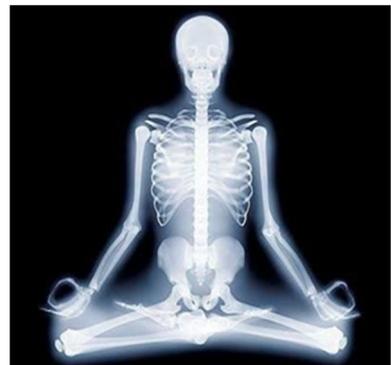
What's your reaction? You may become anxious. You may become scared. You may even hurt just thinking about it.

Now what if the person in the white coat tells you your test results but at the same time tells you degenerative discs are part of the normal aging process, are not a cause of your pain, and there is nothing to worry about?

Makes sense, huh? It's called the nocebo effect – the expectation of persistent or worsening pain. And it can sometimes cause a diagnosis to do create fear and do more harm than good.

You're not your x-ray

MRIs and other imaging tests, like CT scans and x-rays, can add to this nocebo effect by medically legitimizing the pain. Testing can be misleading and open to interpretation – finding something wrong even when there is no pain or showing nothing wrong when there is pain.²



Take back pain, for example. While back pain is a common medical complaint, there often is no specific cause for the pain in up to 85% of cases³ with poor correlation between the presence of imaging abnormalities and pain.⁴

In fact, abnormalities seen in imaging tests are often part of the normal aging process.⁴

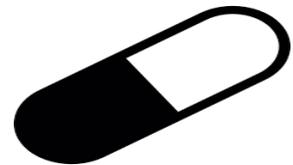
It's no wonder how it can become easy for someone with chronic pain to overutilize the medical system looking for a biological cause and a solution to their pain.

That same overutilization can lead to more diagnostic testing and potential unhelpful or even harmful treatment options – leading the person to worry even more

There's no magical pill, procedure, or intervention

Medical professionals don't have all the answers, nor do they have all the cures.

Chronic pain often doesn't have a clear physical cause. And when it does, there aren't always solutions to the cause.



To date, there is no magical pill, procedure, or other intervention that makes chronic pain disappear. While our current biomedical treatments are good, they provide minimal 24/7 pain relief and can come with 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 pain and improve our lives. **Read on.**

Opioids aren't the best or only answer

Opioid medications have proven most valuable as treatment for short-term acute pain and cancer/end-of-life pain, not for long-term chronic pain.

While some chronic pain patients report improvement with opioids, there haven't been any conclusive long-term studies showing the effectiveness of opioids in relieving pain and restoring function.^{5,6}

In fact, a recent 12-month study showed opioids are no better than non-opioids for chronic back pain or hip or knee osteoarthritis pain.⁷

Opioids also come with risks:

- Side effects – including 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 symptoms.
- Hyperalgesia – Long term use of opioids can make people more sensitive to pain.
- Addiction – compulsively seeking out the drug (patients who take opioids are not all addicts).
- Other complications – including anxiety, depression, heart attacks, sexual problems, respiratory failure, and increased risk for accidents.

The use of opioids is a physician-patient decision based on risk and reward. And if used as therapy, should be part of a comprehensive pain management plan. Any tapering should be done with oversight and alternative treatment. Chronic pain patients shouldn't be expected to abruptly stop opioid therapy.

Pain is an experience – treat the person, not just the body

We're more than our bodies. We aren't machines. Yet, we've been typically treating chronic pain only from a biological anatomical perspective – possibly missing two-thirds of potential pain treatment.

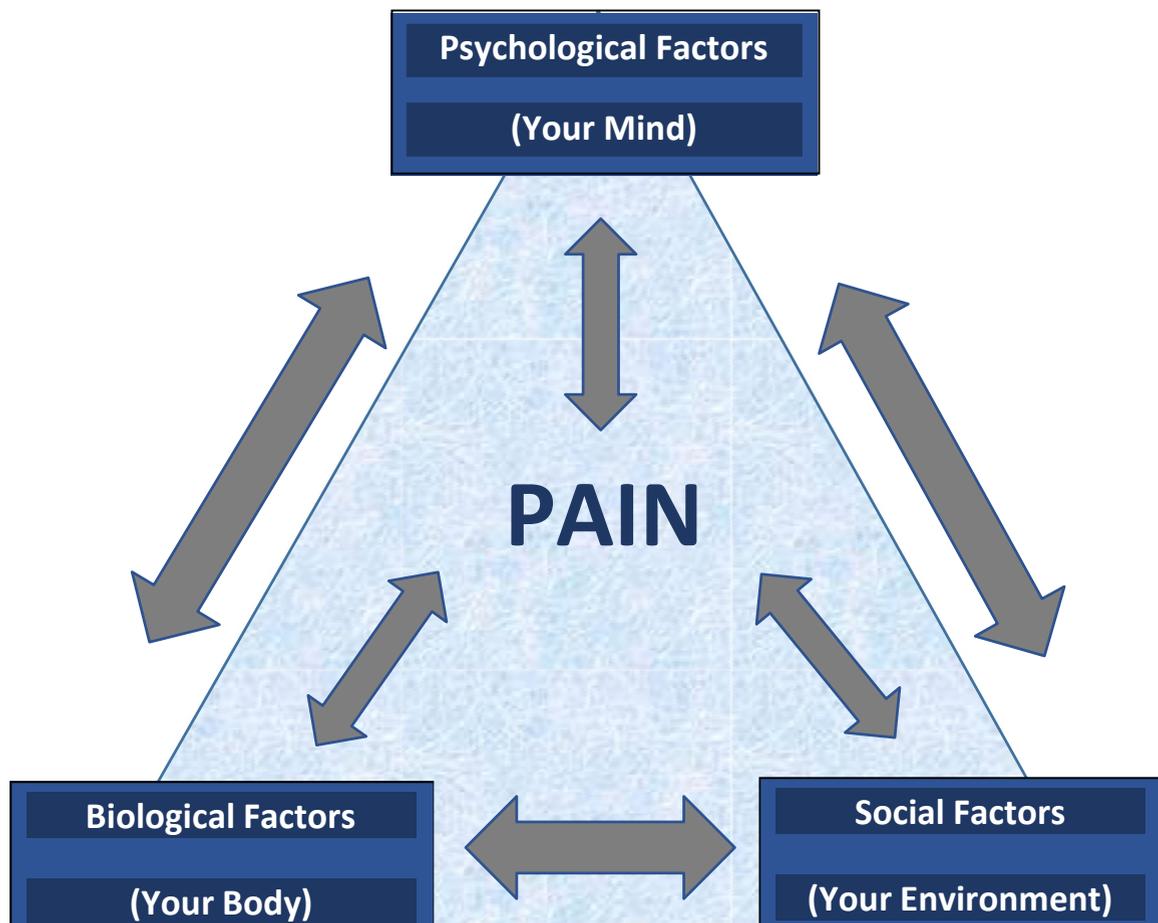
Enter the biopsychosocial (BPS) model of pain.

This model of pain stresses a holistic look at the experience of chronic pain. It not only looks at the biological factors (injury, tissue damage, etc.) but also how our emotional well-being and our social situation influence how we're affected by chronic pain.

**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 model of pain.

Biological

The biological component of the pain experience refers to the physical body, genetic predispositions, and any correlating tissue damage, infection, or other physical stressors. It's what many people typically 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 or other tests have you had 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 worse it can feel and adversely impact your quality of life. It's no wonder chronic pain patients are four times more likely to have depression or anxiety than patients 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 and how much it hurts?
- 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?

Learn more in the Change Thinking, Change Life section of this book.

Social

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

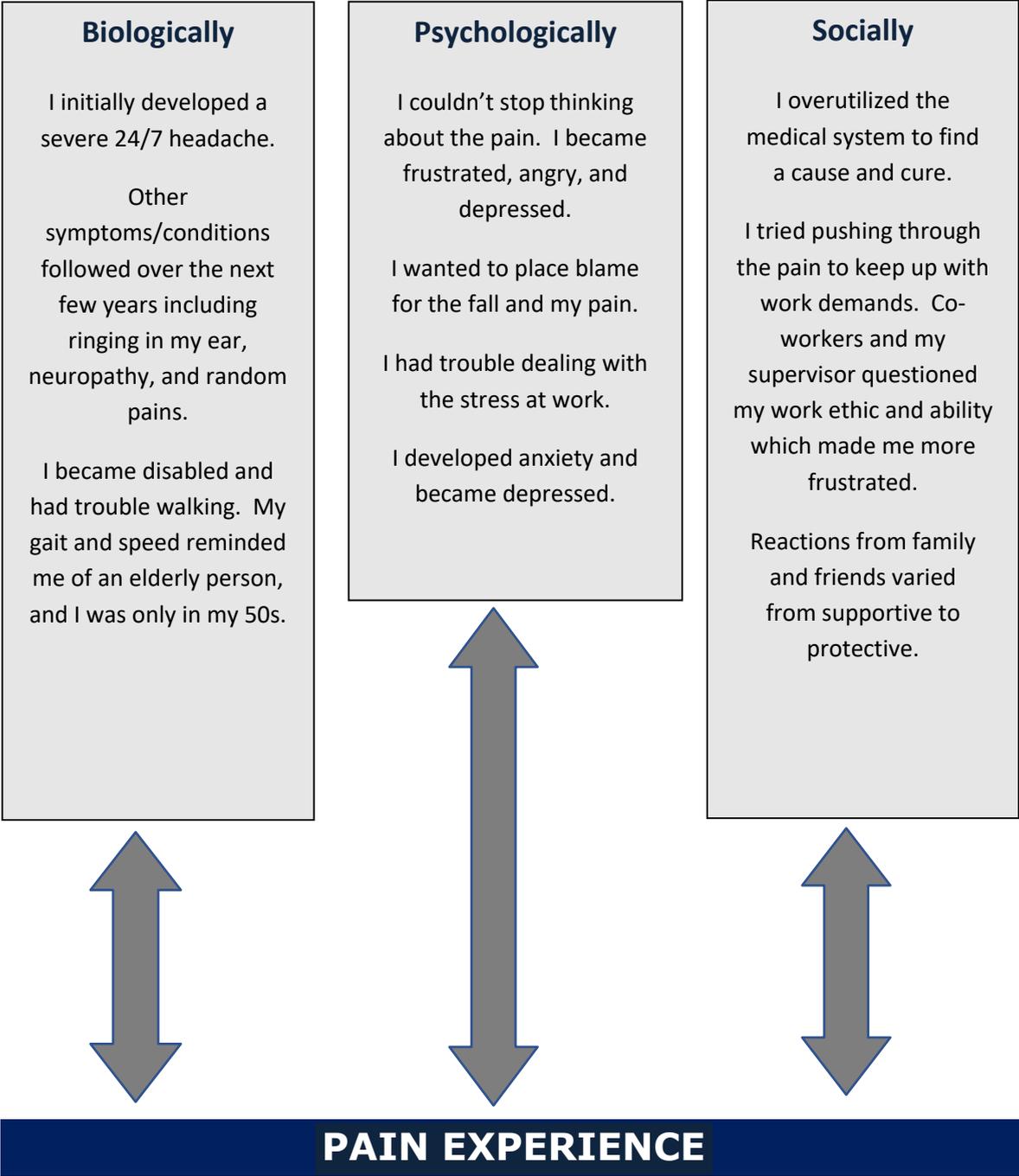


To better understand this part of the BPS model and how it applies to you, ask yourself:

- 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, like exercise, hanging out with friends, doing hobbies, or going to movies?
- Have you become isolated or have others isolated from you?
- Do you have issues at work or have lost work or had to go on disability due to the pain?

Within the biopsychosocial model of pain, each of these three factors play off each other to create the pain experience. I'll use my fall as an example on the next page.

My BPS Example

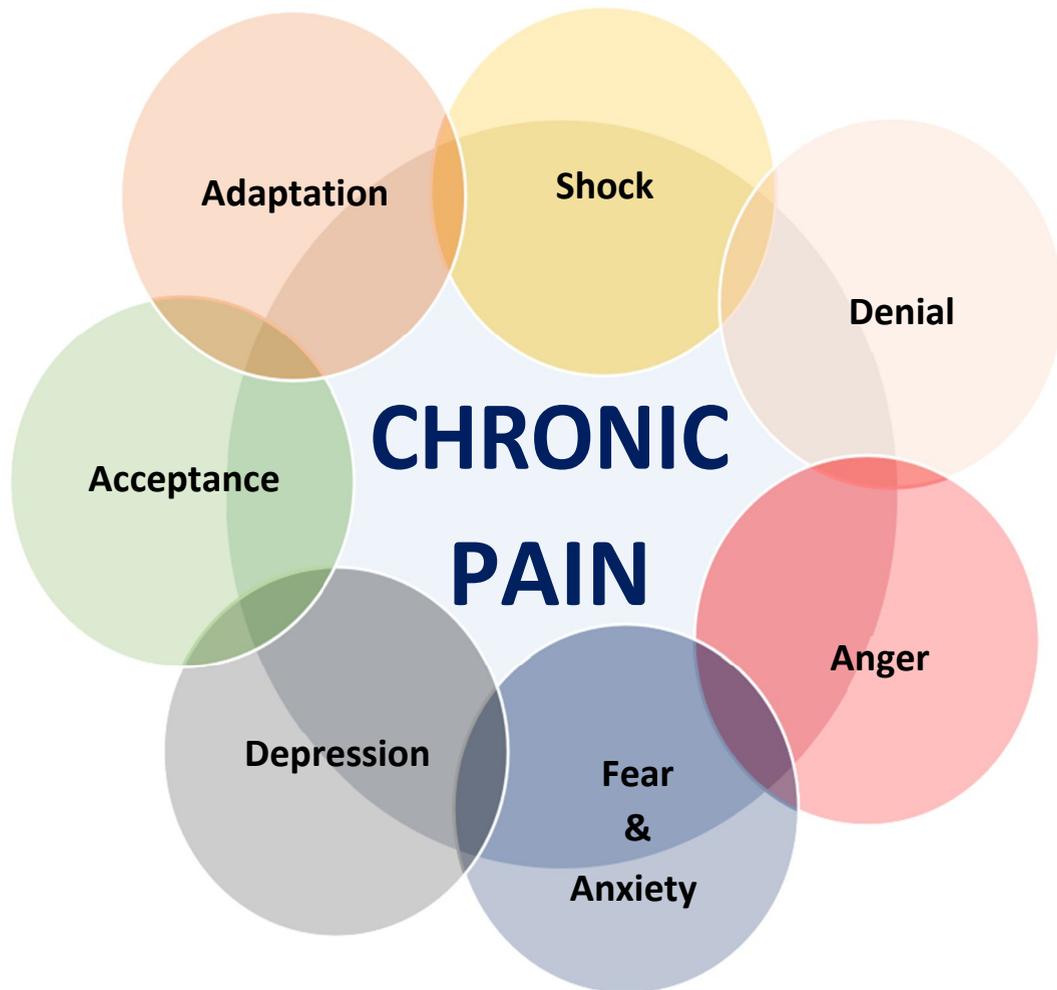


Chronic pain is a journey

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

1. **Shock:** You realize your pain has become chronic. A doctor may have told you may have pain for the rest of your life, or you will never get better. You may even have been told you might not be able to continue to work.
2. **Denial:** You become defensive. You may question the doctor's skills and/or diagnosis. You may start bouncing between healthcare providers and other clinicians to find a cause and cure.
3. **Anger:** You look for blame. You may get mad at a doctor or even at yourself wondering what they did or what you did to cause the pain.
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 those changes. You can become anxious and stressed about not being able to live up to expectations or paying medical bills, etc.
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 accept the reality of your situation and recognize chronic pain as your new normal. The pain may never go away. It is permanent. 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.

The Pain Journey



3 ACCEPT PAIN

"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

It's often the struggle with chronic pain that's the worst part of having pain, not the pain itself. The struggle makes it easy to become preoccupied with the pain, distressed by the symptoms, and feel like a victim.

To minimize the struggle, it's helpful to come to terms with the pain as your "new normal" – accepting the pain as a permanent part of life with no immediate cure – and learning to live life despite pain.

Take note of the pain, accept it, then let it go. Just like the glass of water in the example on page 19, the longer you hold onto the stress and worry associated with chronic pain the heavier and more disabling the pain can become.

Take control the wheel

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 our pain experience and our symptoms by taking away the control the pain has over us.



There's a sense of relief when patients stop fighting the pain and accept the pain – no longer going through the emotional and financial costs associated with more doctors, more testing, more medication, and more procedures.

Accepting pain doesn't mean:

- Being okay with the pain.
- Giving up hope of improvement or being pain-free someday.
- Resigning yourself to a life of misery.

Instead, accepting pain is about grieving your losses, moving forward, finding joy, and leading a fulfilling and functional life, despite the pain.

Stress amplifies the pain experience

Like, pain, stress is a normal body response. It help us in times of flight or fight and acts as a signal to protect us from danger.

But when we become over-stressed by pain and normal daily life, the stress overworks the body – putting it on high alert – making the pain worse.

And when the pain worsens, we become more stressed. It's a vicious cycle.

Hurt doesn't always mean harm

While all pain hurts, not all pain is an indication of damage.

By being able to tell the difference between new acute pain and chronic pain, you can change how you react to chronic pain by not being so guarded or worried about it – reacting with feelings of calm and safety instead of fear and danger.

We know what to expect from our pain by the very nature of it being chronic or ongoing. It's not like getting burnt, twisting an ankle, or getting stung by a bee that needs protection until the injury has heals. Of course, any unexpected new pain should be investigated.

How Heavy is This Glass of Water?

The weight of the glass or the amount of the water doesn't really matter.

What matters is **how long** you hold onto the glass.

The longer you hold the glass, the heavier it will feel.

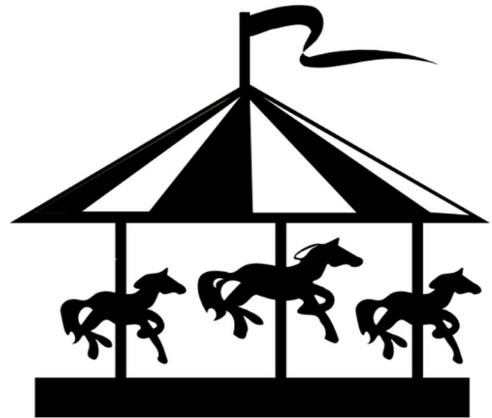
The same holds true for stress, worry, and pain.



Get off the pain merry-go-round

No one likes pain. And we'll do almost anything to find the cause and a solution.

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 having surgery or surgeries.



While some of these might help, some 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 lives – changing who you are and what you feel.

Your, time, job, money, relationships, family, friends, self-image, independence, and sex life can all be affected.

It's normal to be scared, angry, and depressed. To grieve your "old" life before chronic pain. Despite these feelings, it's important to move forward, make room for the pain, and heal from your emotions.

You aren't your pain. It doesn't define you.

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

Ability is the fact of being able to do something. Desire is a want to do something. Focus on what you can and want to do - not your limitations. Don't compare yourself to the past. Keep moving forward.

Don't be the victim

Pain makes it easy to feel powerless to change our situations and to become victims – placing blame on the medical community, the 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.

It can become easy to spend countless hours stressing about what we believe are the wrongs against us. Only to build anger and resentment while preventing healing and negatively affecting both our physical and mental health.

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

Chronic pain cause us to be over-protective.

Our natural reaction to pain is to avoid activity that worsens the pain or what we think might do further damage.

When we become overly fearful, rest, and stop doing things in anticipation of chronic pain; we can make things worse and continue the cycle of pain.

We end up reducing functional ability, as well as losing strength and stamina. And we don't get involved with the social, leisure, and work activities we enjoy.

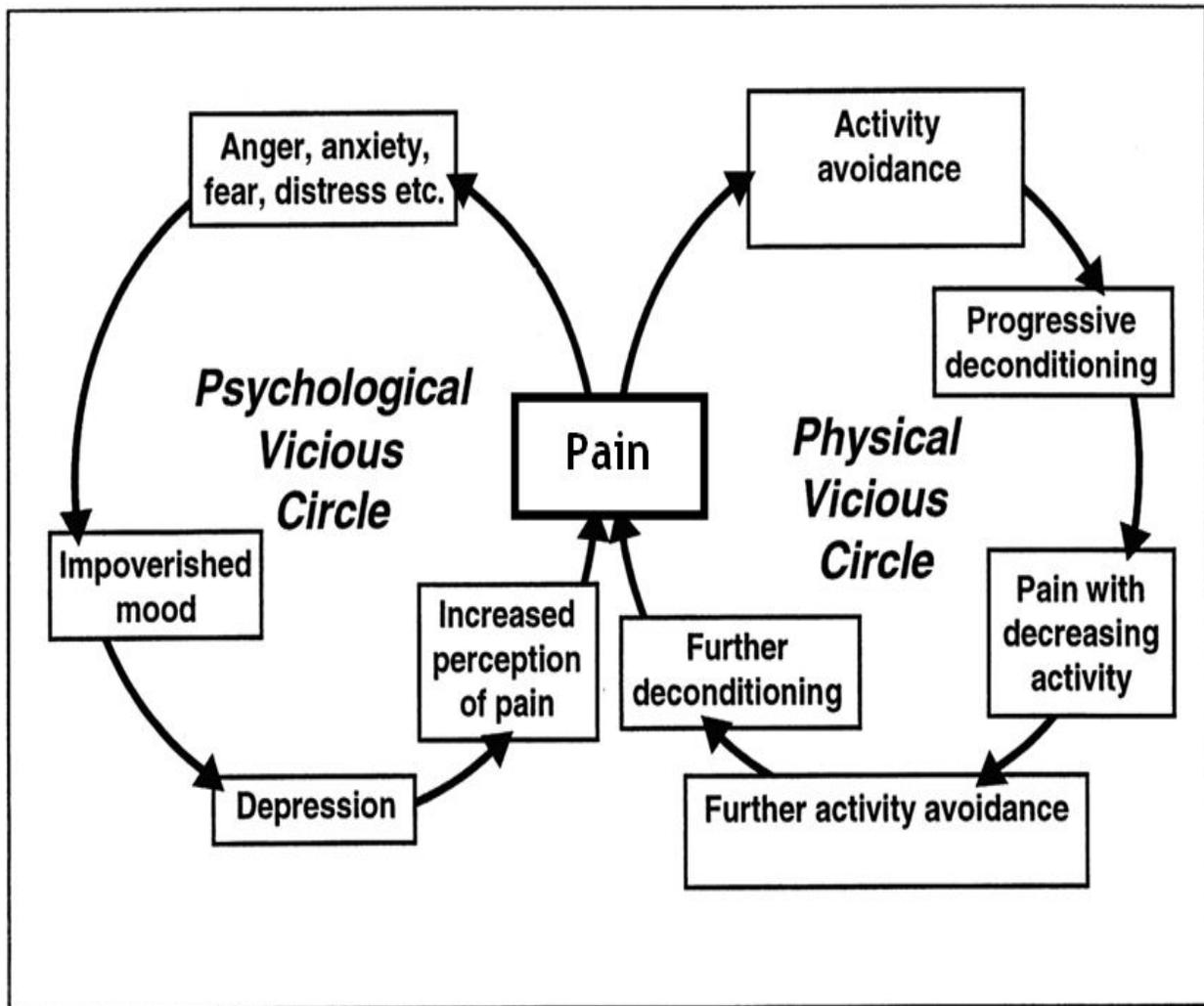
Costs of Inactivity

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

The graphic on the next page shows how the cycle of pain works. You'll find tips to help become more active in the Manage Chronic Pain section of this book.

Stay active, despite pain

The Pain Cycle



Adapted from Cooper, Booker and Spanswick, 2003

Pain is Inevitable.

Suffering is Optional.

We all experience pain. It's part of the human condition. But it doesn't mean we have to suffer.

Pain is possible without suffering. Take eating a jalapeno for example. It can be painful, but we don't suffer.

The choice we have as humans is how we respond to the pain. Back to the jalapeno example. We enjoy the pain of the hot pepper because we enjoy the taste of the pepper. We don't suffer.

Bottom line: we can either choose to suffer in pain or we can choose to live life, despite the pain.

For many people with chronic pain, a vicious circle can form between pain and suffering.

Research has shown the psychological and social distress associated with pain is often more important to the pain experience as the perceived pain severity.⁸

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

Manage expectations

It's important to manage the expectations of chronic pain treatment by both the doctor and the patient.

Since chronic pain often has no cause or cure, zero pain is an unrealistic expectation. We've been trying to do that for years. With little to no success.

Expectations are more realistic when they include improved functioning and higher overall quality of life and not just a cure.

Take responsibility

We must accept responsibility to make the most of our lives, despite the pain. It isn't the responsibility of the medical profession or the pharmaceutical industry. And it isn't the responsibility of our families and friends.

The power is yours. You can stop the cycle of pain.

There is hope for improvement and a better life.

The power is yours.

You get to choose how you want to live in the present.

Yesterday was history.

Tomorrow is a mystery.



Today is a gift.

That is why we call it the present.

"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

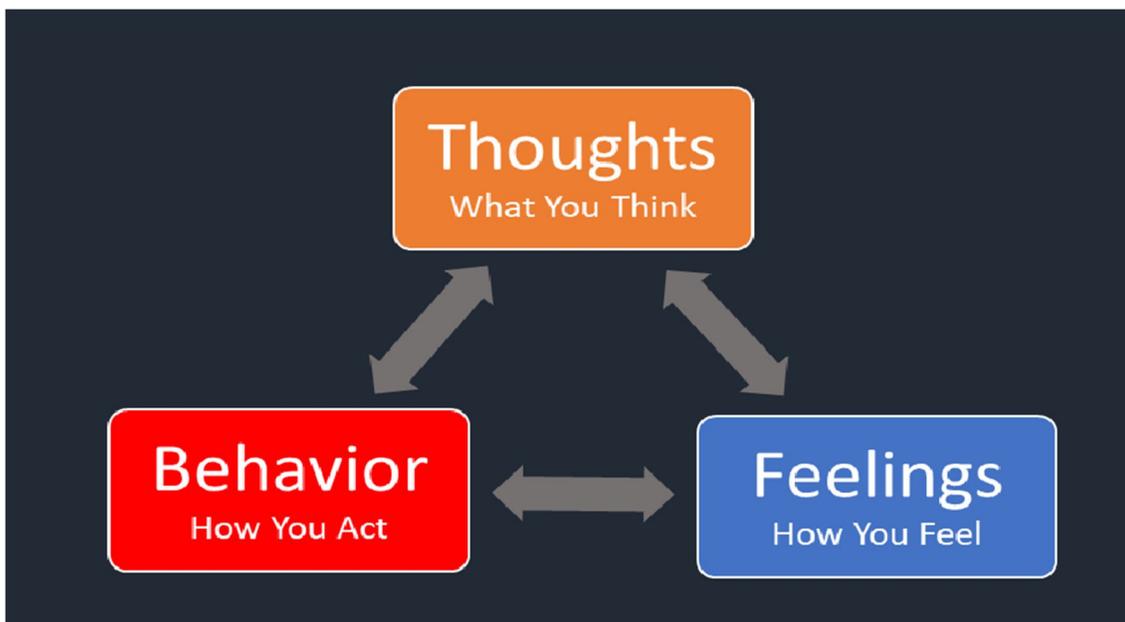
4 CHANGE THINKING, CHANGE LIFE

How much time do you spend each day thinking about pain?

It's easy to become pre-occupied with chronic pain. To feel distressed, to give up, and become a victim just based on how much attention we give it.

The good news is we can train our brains to change the way we think, feel, and behave around chronic pain with a form of psychotherapy called Cognitive Behavioral Therapy (CBT) to help break free from the chronic pain cycle while improving daily functioning and quality of life despite the pain.^{9,10} CBT helps calm over sensitized nervous systems and reduce pain signals in the brain.

Best yet, CBT is a do-it-yourself therapy. You can use it anytime. You don't need help from anyone once you learn it. And there are no negative side-effects.



How we think about pain affects us

*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.*

Do these statements sound familiar?

They're examples of negative thinking, also referred to as negative self-talk. This type of thinking increases focus on the pain, reinforces it, and can actually make the pain feel worse. All while zapping needed energy supply.

Negative thinking leads to rumination and brooding. It fosters anger, worry, frustration, and hopelessness. And it causes what experts' call pain catastrophizing — a natural exaggerated emotional negative response toward actual or anticipated pain.

Catastrophizing jumps to the worst-case scenario. It quickly becomes gloom and doom, breeding more negativity. You become fearful of the pain. You worry about all the bad things that might happen because of the pain. You're more likely to choose negative thinking over positive thinking. And you can feel helpless to manage the pain.

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.¹¹

Reducing negativity can help pain feel less bad.

Change negative thinking

It's okay to talk about chronic pain in a general or educational sense just like we do any other topic in a conversation. Our emotions stay in check.

What's not okay is "stinking thinking" – verbally expressing pain, dwelling on it, complaining about it, wallowing in it, or placing blame for it. At times, we can be our own worst enemies – being overly critical of ourselves. Which only adds to the emotions and fuel even more negative thoughts.

- 1. Identify negative thoughts.** Negative thoughts play off our emotions and can often re-occur for no real reason. They work against us instead of for us.
- 2. Challenge negative thoughts.** Ask yourself: 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 non-judgmental. You aren't a bad person for thinking them.
- 3. Replace negative thoughts.** Replace these thoughts with positive and more realistic thoughts 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 thought examples are provided on the following page.

Other helpful tips to shift negative thoughts:¹²

- 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.

NEGATIVITY



UNINSTALLING

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 biomedical treatments that might help me.	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 down 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 be able 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 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	Though my pain is strong today, it's a 'false alarm', so I'll 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 energy to do everything I want to do each day.	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 type 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, like volunteer.
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. There's no problem that is hopeless.

Change negative behavior

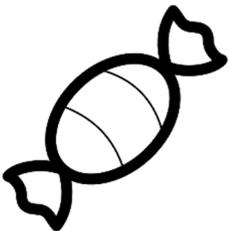
What do you do and say when you hurt?

You may moan or groan. You may make a face and grimace or wince. You may touch or rub the area that hurts. You may stop what you're doing and limit activity. You may complain. You may even say a few choice words.

The body's natural vocal, verbal, physical, emotional, and social reactions to pain are called pain behaviors. They're our ways of expressing our pain. And they can become over-exaggerated catastrophic responses to the pain.

While fine for acute pain like touching a hot stove, we know what to expect with our chronic pain. It shouldn't be a surprise.

Pain behaviors place undue focus on chronic pain and reinforce the pain circuits in our bodies – amplifying the pain and leading to emotional distress and anxiety. They tell your brain how to react the next time you have pain. You not only learn the pain; you learn the reaction.



Just like a kid screaming for candy at the store. If you always buy the child (in this case, pain) candy when they scream, they'll continue to scream each time you take them to the store until they get candy.

While it takes time and practice, eliminating pain behavior can help make the pain less intense and make it safer for us to become more active which in return can make our lives better. ^{9,13}

And what do pain behaviors tell others around you? How do they react to your demonstrations of pain? They may become confused, over helpful, over cautious, or over critical. They may even stop interacting with you.

What you think and do can worsen pain
and increase suffering.

No whining allowed.

PAIN BEHAVIOR: 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	Clinch fists, bracing, hold breath, restlessness, rubbing, slow movement, tears, tense muscles, turn red or pale
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, this sucks, 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, not grooming, withdrawing from activity

Don't share pain

While pain talk can help us validate our pain, it has been shown to worsen pain. Conversely, well talk has been shown to reduce pain intensity.¹⁴

You can't make positive steps in your life if surrounded by negativity. Stay away from people who only want to complain about pain. And don't share your pain with others with pain talk unless there is a positive goal associated with the talk.



Instead of talking about your pain, talk about things you enjoy and find meaningful. Fill your life with joy and hope!

It's natural for people to ask about your pain. Change the conversation. Thank them for asking then tell them you don't want to focus on the pain. Instead of talking about the pain, suggest talking about what you are doing and what you have planned.

Remember, pain doesn't define us. We're more than our pain.

I have seen way too much counterproductive pain talk in many of the Facebook pain support groups. That's why I started my own support group where we try to limit complaining, woe is me, and negative talk. The group is called **Chronic Pain Champions – No Whining Allowed**.

Don't track pain

It's common for chronic patients to keep a pain diary to record details about their pain, including symptoms, pain levels, daily activities, and treatments.

In fact, there a variety of new apps to help us.

But beware of the extra attention. Pain diaries can make pain worse.¹⁵

Research has shown tracking pain adds more focus on the pain, amplifies symptoms, and slows recovery.¹⁵ I know it did mine. I was constantly thinking about the pain and my symptoms to document them in my diary. All it did was make me hurt more and increase my suffering.

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 it's going to go away with wishful thinking. And it doesn't mean you have a psychological problem or that it's just 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 means you're taking control – using more of the available tools to manage your pain. You'll learn about those in the next chapter.

Make a commitment

CBT works but it takes work. To be effective you need to make a commitment to it and believe in it. See a licensed CBT counselor, show up for therapy, and practice what you learn in therapy at home.

Pain rehabilitation programs generally offer some type of psychological training, like CBT. Learn more about pain rehabilitation in the next chapter.

Where there is pain, there is gain

Though 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 strength learning we're the hero by being stronger than our pain, and not the victim. And we can gain new purpose. Just to name a few.

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

5 SELF-MANAGE CHRONIC PAIN

The pain may never go away. Just like the rain, you can't stop it. But if you have an umbrella, you can stop from getting soaked.

No matter the amount of pain, there are CBT-based self-management tools you can use to help calm the mind, calm the body, make it easier to function, and live your life more fully. All it takes is time, patience, and practice.



Plan and prioritize

Planning and prioritizing reduces stress, lessens the risk of over-activity, and increases your chance for success.

Set attainable goals and write them down along with what you're going to do to achieve them and when you'll achieve them. Writing goals helps instill them. Plus, you can use your notes 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** - specific, measurable, achievable, relevant, and time-bound.

- **Specific** – What do you want to do? What action 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 by end of week to 5,000 steps a day.
- Do deep breathing for three minutes three times each day for next week.
- Read three articles about cognitive behavioral therapy by end of the week.
- Plan a social event to visit in-person 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 such as stretching, hygiene, deep breathing or going for a walk that help you reach your goals. Like writing goals, scheduling helps keep you on track.

Physical activity, movement, and exercise

While it may seem counterintuitive; physical activity can reduce pain as well as increase pain thresholds.^{16,17}



In addition, it also helps improve health, balance, improve conditioning, manage weight control, improve sleep, and increase flexibility.

Challenge any negative thoughts of not being able to be physical. You're probably already incorporating physical movement in your daily activities like getting the mail, shopping, and housekeeping.

It doesn't have to be daunting.

Maybe start with light, fun, and easy to do activities, like stretching, yoga, tai chi or going for a walk and build up over-time. If you have an activity tracker, set a daily 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.

A 2015 review of 26 studies found that in people who have chronic muscle or joint pain, those who walked for exercise had less pain and better mobility than those who didn't exercise.¹⁸

Don't get frustrated if you have difficulty or experience issues when you start to get more active, especially an increase in muscle pain. That's normal as 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. But moderate and modify activity to not overdo it – learn more about moderation and modification later in this chapter.

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

Movement can make life better.

Relax to relieve stress

Pain, stress, and tension are closely related. Muscles tighten and put pressure on nerves resulting in even more pain.

It's possible to activate your body's natural relaxation response help reduce the tension using mind-body tools like:

- Deep breathing (also called diaphragmatic breathing, abdominal breathing, and belly breathing) – is easy to learn and can be done anywhere.
- Yoga and tai chi – can be modified, if needed, to accommodate individual needs, like chair yoga or tai-chi chih (a simplified version of tai chi).
- Meditation – requires you to redirect your attention.
- Passive muscle relaxation – you mentally relax your muscles from head to toe.
- Progressive muscle relaxation – you 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 it slowly fill your lungs.
3. Hold it before exhaling through your mouth or nose.

Try to do this for 5 minutes, 2-3 times a day or when you need to relax.

Calm the mind. Calm the body.

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 lessen symptoms.

Ways to pace activity include:

- Setting time limits – gradually increasing the amount of time
- 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

But be careful not to let pacing become an excuse for not being active 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 protect itself. Our bodies become over-sensitized.

Pacing should instead be 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.

Keep moving forward!

Modify what you do

Why make things harder than what they are? Techniques like breaking up activities and good body mechanics make things easier, not harder.

This is especially holds 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.

Distract yourself – change your focus

One of the easiest, most effective, and most recommended ways to manage pain is to change your focus and attention to distract yourself from it.

Paying attention to pain, amplifies the pain. Whereas distraction from pain, makes it less noticeable.

And it's not just a bunch of psychobabble.

Scientific research using MRIs has found mental distraction inhibits the response to incoming pain signals at the earliest stage of central pain processing – reducing expected pain behavior.¹⁹

Some ways to distract yourself:

- **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 to help us feel better.
- **Talk with a friend** – A friendly face or voice can be calming. Call or visit a friend. Just 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. 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 games. Just make sure to make any activity low stress and enjoyable.

Put pain in the background.

Be mindful

It's easy for our mind to wander and lose touch with the things we enjoy.

Mindfulness redirects the mind from the wandering negative thoughts in our head so we can enjoy the present with no judgement, 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, how we breath, and what the air feels like coming in and out of our bodies. We can also practice mindfulness when listening, walking, or doing simple things like playing with our pets. Best yet, it's free and requires no special equipment.

Research has shown mindfulness to improve disability, quality of life, self-efficacy, pain catastrophizing, and depression in migraine patients.²⁰

Get the best of both mindfulness and exercise.
Practice being mindful while on a walk.

Be kind to others – 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 doesn't excuse or justify past actions. Nor does it release any responsibility.

Forgiveness is a gift to us. We no longer have to carry the burden of resentment and negativity. And we free ourselves to move forward.

Be grateful

When times get tough, get grateful.

Being grateful won't make pain disappear but can make it much easier to live with by releasing suffering, changing perspective, and boosting mood.

Some ways to practice gratefulness:

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



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 – everything doesn’t have to be in place.
- Say “no” if you need to.
- Accept help.
- Forgive yourself (sometimes we are our own worse critics).
- Eat healthy. Don’t smoke. And don’t drink. Diet, nicotine, and alcohol can worsen the pain.
- Sleep better (see tips on the following page).
- 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 what you’ve lost.

Sleep Better. Feel Better.

Chronic pain can interrupt sleep while poor sleep can worsen pain.

Tips for Better Sleep

- Keep a regular sleep routine. Go to bed at the same time each day.
- 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 use of nicotine, alcohol, and sleep medications.
- Avoid exercise 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 lay 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 your quantity or quality of sleep – 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 that time now by putting together a kit to help you get through the rough times. Inside this kit could be a letter to yourself reminding you to stay positive, a list of your positive qualities and accomplishments, some favorite candy, music, photos and whatever else provides short-term comfort.

Explore pain rehabilitation

Talk to your doctor about the biopsychosocial model of pain and pain rehabilitation.

Pain rehabilitation goes beyond medicine and medical interventions – and crosses different disciplines. It doesn't just focus on removing the pain. It focuses on the patient and how they can play a role in their own pain management.

It's a proven approach – benefitting patients while reducing costs and reliance on the medical system.^{21,22}

In addition to their general efficacy, interdisciplinary chronic pain rehabilitation programs can be effective at weaning patients off opioid therapy with long-term improvements in pain, mood, and function.²³

Having gone through the 3-week outpatient Mayo Clinic Pain Rehabilitation Center, 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. I highly recommend this program!

Read about my experience at Mayo Clinic in an article I wrote for Practical Pain Management. You'll find a link to it in the Education section of chronicpainchampions.com

Do I still have pain? Of course, I do. But I've learned to live well, despite the pain.

Major pain rehabilitation programs are available in the United States and around the world. Links to select programs are provided in the Resources section of chronicpainchampions.com. Local and regional programs may also be available.

Treatment and Cost-Effectiveness of Comprehensive Pain Programs for Chronic Nonmalignant Pain

Measure	Treatment Outcome Results	
	Comprehensive Pain Treatment	Conventional Medical Treatment
Increase in activity	65%	35%
Return-to-work	66%	27%
Pain reduction	20-40%	30% (with opioids)
Medical cost savings	68%	-

Gatchel RJ, Okifuji A. Evidence-based scientific data documenting the treatment and cost-effectiveness of comprehensive pain programs for chronic nonmalignant pain. J Pain. 2006;7(11):779-793.

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?

6 LEARN MORE, GET MORE

Visit [chronicpainchampions.com](https://www.chronicpainchampions.com) to read my blog, access articles and videos about pain, join my Facebook support group, get links to self-management tools, and much more.

<https://www.chronicpainchampions.com/>

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What's inside

While a cure for chronic pain is rare, there's still hope for improvement and a better life for chronic pain patients. Recovery is possible!

This book is my experience as a chronic pain patient, my research, and the biopsychosocial approach I use to manage pain based on what I learned at the three -week Mayo Clinic Pain Rehabilitation Center.

It provides a simple, yet understandable explanation of pain, diffuses the fears of chronic pain, and provides tools to help self-manage the pain and increase functioning.

I hope you find the book helpful.

I make no money from the book. A free PDF download is available at chronicpainchampions.com.

It's possible to live a fulfilling life,
despite chronic pain.

Version 4

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