

Department of Psychological Services

at the Center for Pain Management



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Pain
is **inevitable.**
Suffering
is **OPTIONAL.**

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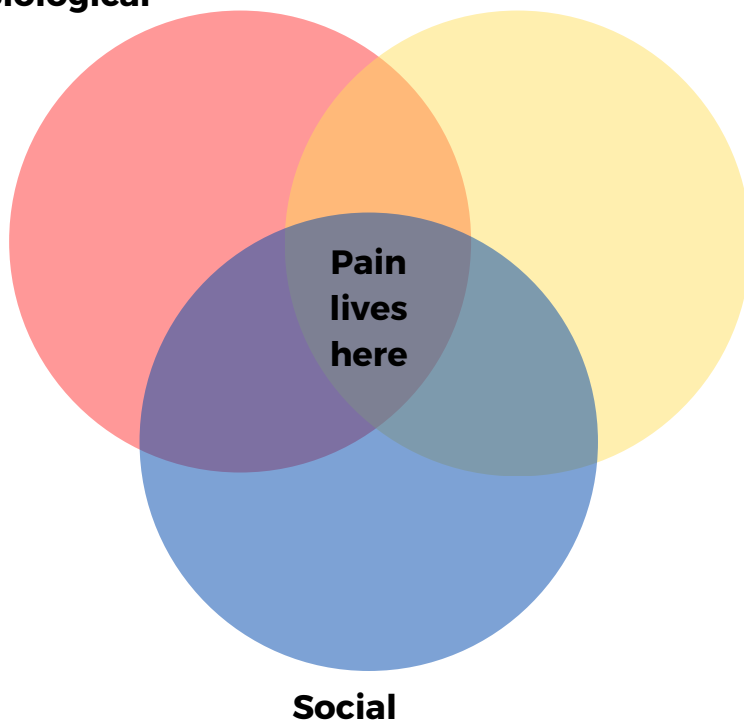
Why See a Pain Psychologist?

Pain is real and it is complex! The causes of pain are biological, psychological, and social. Likewise, pain can affect you physically, psychologically, and socially. Can you think of a time when you were stressed and then developed a headache?



Biological

Psychological



Pain psychologists take all these pieces and determine ways to improve your pain management. We treat the whole person, not just the site of the pain. We work collaboratively to reduce the impact of stress and other factors on your pain, so that you can create a life worth living even when there is pain. **By finding the best ways for you to manage your pain, pain psychology can help improve mood and reduce the impact of pain on your mental health and social relationships.**

How Current and Past Experiences Impact Pain

Stressful events from our past can affect the way our brain works. These stressful life events actually change our brains! Following stressful events, our brain may be on the lookout for things that seem threatening (this is called **hypervigilance**) and normal stimuli can be interpreted as extremely dangerous.

The same thing can be said for pain. For example, think of how a paper cut can feel like nothing or be extremely painful.

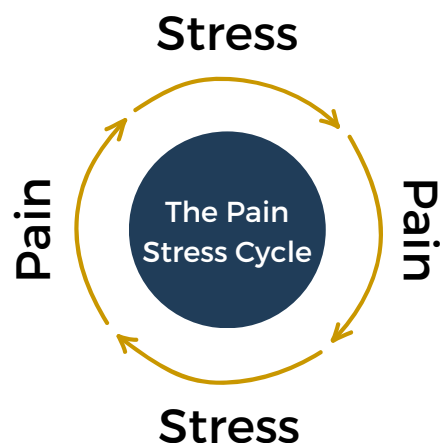
People vary in pain sensitivity. What is extremely painful for one person may not be painful for someone else.

Stress can affect your sensitivity to pain and therefore increase the likelihood that you perceive pain.

- For most people to experience pain, the discomfort has to get really intense before the brain determines there is pain.
- When we have stress, sensitivity to pain decreases and the brain is likely to decide there is more pain than before.
- Just a bit of discomfort can be interpreted as dangerous, and is interpreted as dangerous and painful by the brain (ex. A touch on the shoulder, walking, clothing on your skin).

The Good News

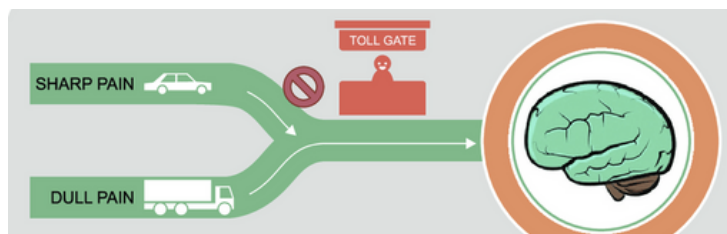
By understanding and managing our emotions about stress and learning new coping styles, you can reduce the pain, discomfort, and suffering that goes with it.



How Pain Works: Gate Control Theory

Peripheral nerves from all over the body run to the spinal cord, which is the first meeting point for the central nervous system. In the spinal cord, you might imagine a series of gates into which messages about pain arrive from all over the body. These gates can be open, closed, or partly open. This is important because messages must pass through these gates to pass to the brain. If the gates are more open, then more pain messages will pass through, and you are likely to experience a high level of pain. If the gates are more closed, then fewer messages get through, and you are likely to experience less pain.

So, how do we open or close the pain gates?



There are three main ways to open the gates to pain, so that more peripheral pain messages result in increased pain. These methods involve how we feel about things, how we think about things, and what we are doing.



1. **Stress and Tension:** All sorts of emotional states can lead to the pain gates being more open. These include being anxious, worried, angry, and depressed. Having significant tension in the body is a common way of opening the pain gates.
2. **Mental Factors:** One of the most effective ways of opening the gates and increasing your pain is to focus all your attention on it. Boredom can also lead to the pain gates opening.
3. **Lack of Activity:** Another factor that seems to open the gates to pain is not to move around, to have stiff joints, and lack of fitness.

In the same way as above, the way we feel, the way we think and what we do can all play a part in helping to close the gates to pain.

1. **Relaxation and Contentment:** Feeling generally happy and optimistic has been found to help to close the gates to pain. Also, feeling relaxed in yourself seems to be a particularly useful way of closing the gates.
2. **Mental Factors:** Being involved and taking interest in life helps to close the gates. Also, if you concentrate intensely on something other than the pain (e.g., work, TV, books), then this can distract you from any pain, helping to close the gates.
3. **Activity:** Doing the right amount of exercise, so that you develop your fitness can help close the gates.
4. **Other Physical Factors:** You may also find that certain types of medication can help to close the gates, as might certain types of counter-stimulation (e.g., heat, massage, TENS, acupuncture).

Gate Control Theory (continued)

Below are just a few examples of factors that may impact your pain:

Factors That May  Increase Pain	Factors That May  Decrease Pain
<i>Physical Factors</i>	
Degenerative changes	Medical interventions
Muscle tension	Relaxation techniques
<i>Thoughts</i>	
Catastrophizing	Having balanced thoughts
Focusing on pain	Using distraction to focus on other things
<i>Emotions</i>	
Depression or anger	Challenging negative thoughts
Stress/worry/anxiety	Exercise and relaxation techniques
<i>Behaviors</i>	
Under- or over-activity	Using pacing regularly
Lack of involvement in hobbies	Increasing pleasant activities
<i>Social Interactions</i>	
Social isolation	Positive time with family and/or friends
Lack of or too much support from others	Volunteering/community involvement

Lamb, Kelly. Cognitive Behavioral Therapy for Chronic Pain (CBT-CB). 2019, <https://slideplayer.com/slide/14282169/>. PowerPoint Presentation.

Opioid Induced Hyperalgesia

How do opioids affect the perception of pain?

Common opioid prescriptions include codeine, methadone, fentanyl, morphine, hydrocodone, oxycodone, and hydromorphone.

Opioids reduce pain in the body by attaching to opioid receptors. This decreases the amount of pain signals sent to the brain. Local anesthetics may block these signals from reaching the brain entirely.

What is opioid induced hyperalgesia?

Let's break it down. *Hyper-* refers to "a significant increase" and *-algesia* refers to your body's response to painful stimuli. So, opioid induced hyperalgesia is a condition in which people who use opioids to treat pain develop *greater sensitivity* to pain.

Although opioid medications are used to reduce pain in some patients, the medications can have the opposite effect and actually increase the level of pain that a person experiences.

Opioid induced hyperalgesia may be at play if a patient is treated with prescription opioids but reports that their pain is not well-controlled, is not significantly improving, or is progressively getting worse. These patients are likely becoming more sensitive to their original pain and may develop new pains. Additionally, patients with this condition may experience more pain than the average person in response to a new injury or painful condition.

Research has found that this condition is more likely to occur in patients who take opioids at higher doses or for a longer period of time, although some patients experienced it after only a few doses. Genetics may play a role in how quickly opioid induced hyperalgesia develops.

Opioid induced hyperalgesia is not the same as tolerance. Tolerance is the decreased effectiveness of a medication over time with repeated use. When tolerance occurs, it may seem like an increase in medication dose will help; however, this is not necessarily true. In the case of tolerance, increasing a patients' dose will likely provide relief for only a very short period of time before the patient experiences another decrease in the effectiveness of the medication. Speak with your physician about opioid induced hyperalgesia and tolerance before making any changes to any prescription regimen.

Central Sensitization In Chronic Pain

"Pain itself can change how pain works, resulting in more pain with less provocation."

What Is It?

Central sensitization refers to a change in the way the nervous system processes pain. Patients with central sensitization are not only more sensitive to things that should hurt (this is called **hyperalgesia**), but also to ordinary touch and pressure that should NOT hurt (a condition called **allodynia**). Patients with central sensitization also have pain that fades more slowly than it would in other people. It is central sensitization that causes chronic pain to stick around even when an initial injury has healed. In this way, central sensitization is a "software" not a "hardware" problem.

How Do We Diagnose It?

Central sensitization is a diagnosis of exclusion, which means that physiological explanations for pain are insufficient in explaining a patient's level of reported pain. Because this experience happens entirely inside of your nervous system, there are no labs or tests used for diagnosis. This DOES NOT mean that your pain isn't real. The pain you are experiencing is very real. The root cause is located in the nervous system and not in damaged tissues. Central sensitization means that your spinal cord and brain are reporting more damage to your body than what actually happened. Therefore, your brain and spinal cord are where the pain is occurring, not just your back, head, stomach, etc.

How Do We Treat It?

Lowering stress, depression, and anxiety can help lower central sensitization pain by helping to close pain gates in the central nervous system. It is important to note that pain in response to central sensitization is unlikely to respond to traditional opioid therapy. Instead, helpful treatments target the brain and the nervous system. These include, but are not limited to non-opioid-based medications, psychotherapy, yoga/meditation, aqua therapy, and other healthy means of "quieting the mind".

What Is The Prognosis?

To manage central sensitization, research and best clinical practices suggest the use of a comprehensive and integrated treatment approach.

Unhelpful Thoughts About Pain

Living with pain can be hard. It can make you sleep poorly, feel tired and irritable, and have a hard time being active or working. It may strain your relationships with loved ones, making it hard to be the kind of friend, parent, or partner you want to be. You may feel stressed, get depressed or notice anxiety. You may develop the belief that something bad will happen, that your pain will never go away, or that there is nothing you can do to improve your pain. All of these responses, while difficult to bear, are normal.

When an individual has these beliefs about pain, we call it **negative pain thoughts or catastrophizing**. Catastrophizing is a set of unhelpful ideas or thoughts about your pain that may make pain and functioning worse! Research suggests that when people catastrophize their pain, they quite often have worse pain that lasts longer! Catastrophizing about pain can take many forms, including: rumination ("I can't stop thinking about it,"), magnification ("this is the worst thing ever,"), and helplessness ("there's nothing I can do change it!").

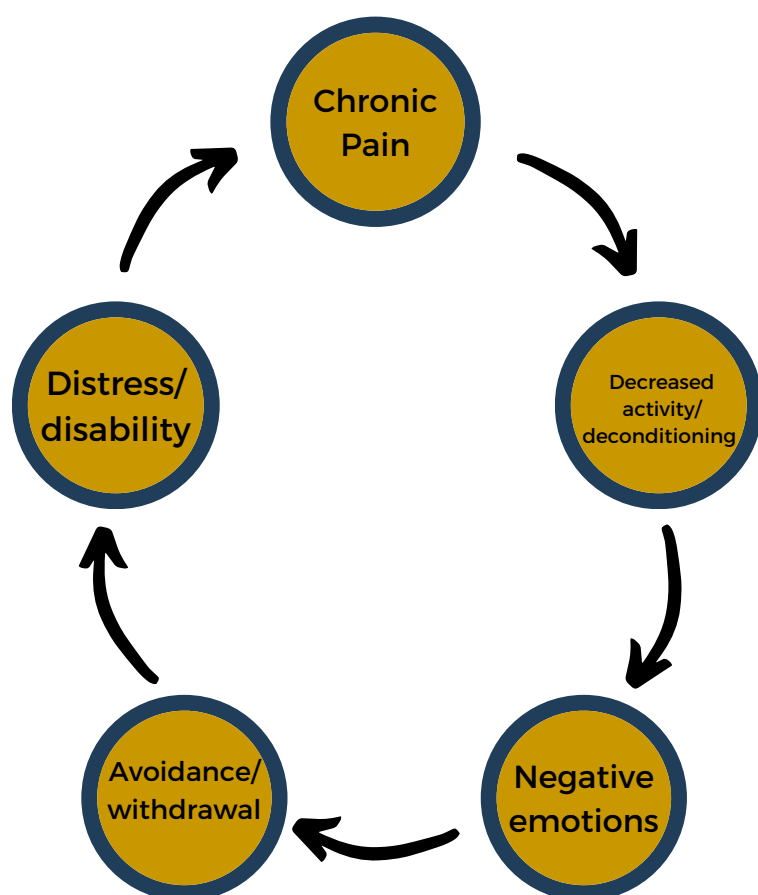
Patients who engage in this kind of thinking can learn techniques to encourage more helpful and encouraging thoughts by working with a pain psychologist.

- One goal of therapy is to change the way you think about pain so that your body and mind respond better when you have pain.
- Another goal is to help you cope with chronic pain by helping you learn to accept negative thoughts and feelings. You learn to base your choices and actions on your personal values, rather than on negative thoughts and feelings.
- Healthy thinking can help individuals be more physically active by reducing discouraging thoughts. Movement is essential because pain can also improve with physical activity, such as walking and swimming, or even chair yoga.
- Changing a way of thinking takes some time. Be patient with yourself as you learn healthy thinking. It may not feel right at first, because you are trying out something new. But with daily practice, it will get easier and feel more natural, and it's something you can start doing today.



The Chronic Pain Cycle

Many people with chronic pain fear that movement will increase pain or cause physical damage/injury. This fear often leads to decreased activity, which leads to physical deconditioning (e.g., less strength and stamina, weight gain). Dealing with constant pain may also lead to negative thoughts and emotions, such as frustration and depression. All of these factors contribute to increased avoidance of people and activities. While this cycle is understandable for those with chronic pain, it doesn't reduce pain! It could actually make your pain and its effects much worse over time. Now that we are aware of the cycle, we must learn how to break it.



The Costs of Inactivity:

- More pain
- Poorer physical fitness
- Less time with family and friends
- Depressed mood or increased stability
- Lower self-esteem
- Increased strain on relationships
- Decreased quality of life

Adapted from Murphy, J.L., McKellar, J.D., Raffa, S.D., Clark, M.E., Kerns, R.D., & Karlin, B.E. Cognitive behavioral therapy manual. Washington, DC: U.S. Dept of Veterans Affairs.

If we understand the cycle, we reclaim the power to break it.

Cognitive Behavioral Therapy

Cognitive behavioral therapy, or CBT, is an evidence-based approach that has been proven effective in the management of chronic pain. CBT for pain management emphasizes an active problem-solving approach to managing the challenges that accompany chronic pain.

CBT therapy includes:

- Learning how to recognize thinking errors and change unhelpful negative thoughts related to pain into more helpful or positive thoughts
- Relaxation training
- Time-based activity pacing
- Problem-solving how to decrease avoidance of activity and reintroduce a healthier, more active lifestyle

One of the main goals of CBT is to provide you with a “toolbox” of skills you can use to manage your pain. CBT therapy involves practices to help you master these skills and introduce them in your daily life. Many of these skills serve to break the chronic pain cycle and close the pain gates. **No matter the cause of your chronic pain, CBT can help you learn how to more effectively manage your pain.**



Skills for Pain Management



What is Mindfulness?

Mindfulness refers to paying attention in a particular way: on purpose, in the present, and without judgment (Kabat-Zinn, 1994).

Mindfulness is a type of thinking that focuses on the here-and-now. When a person is mindful, they are not thinking about the future or the past, but are aware of the thoughts, feelings, and actions that are going on in this specific moment. Mindfulness is about purposefully paying attention in the present moment. The opposite of *mindfulness* is *mindlessness*. We've all experienced mindlessness - being on autopilot, feeling numb or detached, or caught-up in our thoughts instead of the activity at hand. The result of mindlessness is that we don't enjoy the moment we are currently experiencing.

Mindfulness is also about adopting a non-judgemental attitude toward our thoughts and feelings. That means that while being mindful, a person does not need to compare, label, or judge his thoughts. While mindfulness can be relaxing, the goal in most mindfulness exercises is awareness.

Skills for Pain Management (Continued)

Examples:

Mindful Thoughts: "I am feeling anxious. I notice that my hand is shaking. I have the thought, "he is judging me."

Non-mindful Thoughts: "I shouldn't be anxious. My hands weren't shaking this bad last week. He doesn't like me and that means that..."

Mindfulness practice is particularly helpful for patients with chronic pain. It involves pausing and noticing what is happening within us and around us as we go through the tasks of the day. We note breathing, thoughts, feelings, sensations, and surroundings. Rather than a mental checklist, we do this with gentle, non-judgemental awareness.

Many people think they're doing something wrong because they can't clear their minds. In mindfulness, we don't try to block out thoughts. Instead, we acknowledge them parading through the mind one by one. We notice what has drawn our attention away from the present moment and then gently refocus our attention.

In mindfulness meditation, there is no objective to achieve anything, such as relaxation or some altered state of being. Mindfulness meditation involves a willingness to simply be with whatever is happening within us and around us - with an open mind. This awareness may cause us to feel anxious at first.

Mindfulness requires courage to see things as they are rather than how we wish they were. The good news is that mindfulness practice helps us have the patience and compassion necessary for positive change, especially as it relates to pain.

Mindfulness Techniques

Mindfulness can often be a confusing concept because many think that the mind must be blank for the practice to be successful. This is a common misconception. You can carry out the practice of mindfulness in many, if not most, of the daily tasks you already do now without completely quieting the mind!

The 3-Step Mindfulness Exercise

- Step 1:* "Step out of "auto-pilot" and bring awareness to the current state and how you're feeling right now.
- Step 2:* Bring awareness to your breathing. Notice your chest rising and falling, belly pushing in and out, lungs expanding and contracting.
- Step 3:* Expand awareness outward; first to the body, then to the environment. Notice your bodily sensation and then move to noticing colors, shapes, textures, etc.

"How" Skills:

Non-Judgementally: SEE but do NOT evaluate; just notice the facts. Focus on the "what", not the "good" and the "bad". Focus on the "who, what, when, and where".

One-Mindfully: Do ONE thing at a time. When you are walking, walk. Eating, eat. Working, work. Put all your attention on that activity.

Effectively: Focus on WHAT WORKS. Assign effort and time to accomplishing your larger goals. Stay away from "good and bad", "should and shouldn't". Let go of vengeance, useless anger, and righteousness that hurts and doesn't work.

Mindfulness Walk: Go on a walk. Start by noticing how your body moves and feels with each step. Then expand your awareness to the environment. What do you see, hear, smell, and feel? This can be extended into other daily activities as well!

Raisin Exercise: Find a raisin. Take the time to really notice and observe the way the raisin looks, feels, smells, and tastes. Utilize all your senses to take in the raisin fully.

Body Scan: Find a comfortable position, either standing or sitting. Take time to notice the rhythm of your breath. Now, begin from either the top of your head or the toes and bring awareness to each area of the body (how it feels, sensation, soreness, tightness, clothes on skin, etc.)

Mindfulness Techniques for Relaxation

Diaphragmatic Breathing (deep belly breathing): Place one hand on your upper chest and the other just below your rib cage. Allow yourself to feel your diaphragm move, causing your belly to expand as you breathe. Breathe in slowly through your nose so that your stomach moves out against your hand. The hand on your chest should remain as still as possible. Tighten your stomach muscles, letting them fall inward as you exhale through your mouth. The hand on your upper chest should remain as still as possible.



Progressive Muscle Relaxation: Start by noticing how your body is feeling right now. Go into yourself and explore... is your body heavy, is it tight, is it tense, is it relaxed, do you feel calm, do you feel anxious? Then focus on one body part at a time (starting with your feet and working your way up to your head). Clench the muscles in one body part at a time. Hold them tight for a few seconds then release. For more guidance through this exercise, ask your psychologist or type it into YouTube or a mindfulness app.

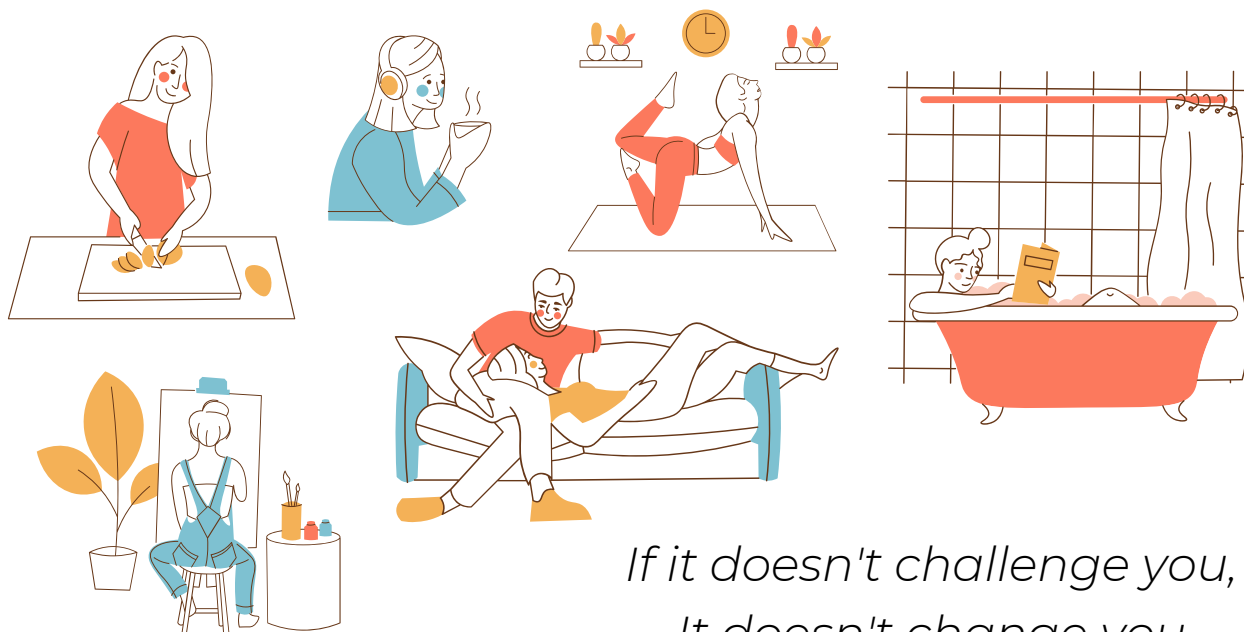
If Mindfulness is of interest to you, ask your provider for information at your next appointment. There are also books, apps, and websites you can utilize to learn about and develop a practice in mindfulness.

The Power of Doing

People with chronic pain are at high risk of leading unfulfilling, sedentary lives that lack the stimulation necessary to compete with pain for attention. This lifestyle, in addition to the loss of interest and mobility that accompanies chronic pain, creates an increase in isolation and, as a result, increases focus on pain. **People with pain that are ACTIVE in recovery report less pain upon return for follow-up appointments compared to people who take a more passive role in their health care.**

Most people are surprised to hear how much harm can come from too much rest. We know that even young, healthy people confined to a bed for weeks experience increased disability and loss of calcium in their bones. The medical term for this is **deconditioning**. Inactivity leads to muscle weakness and muscle loss. Muscle weakness and loss lead to changes in posture, which in turn leads to unhealthy pressure on joints. As a result, the pain is worse. Additionally, circulation can also become impaired as the heart weakens, triggering poor blood supply to painful areas, which also increases pain. Finally, inactivity also decreases flexibility, and when activity resumes, one often overdoes it, which strains muscles and joints, thereby increasing pain.

Unfortunately, many medications used (opiates, muscle relaxers, benzodiazepines, and other anxiety medications) increase fatigue and inactivity, which chronic pain patients should avoid. So remember - easy does it, but DO it.



*If it doesn't challenge you,
It doesn't change you*

Activity Pacing

The Pain and Rest Cycle

- When pain and fatigue set in, the natural response is to rest.
- Sometimes it takes much rest to feel better.
- When you rest for a long time, very little gets accomplished.
- Once rested, people with pain sometimes become overly active to make up for lost time, causing increased pain and fatigue and restarting the cycle.

How to Use Activity Pacing

1. Identify your pain rating (0-10 scale).
2. Identify the pain rating at which *your* pain becomes overwhelming (0-10 scale).
3. As you engage in activity, monitor your pain rating. When it becomes one or two points less than "overwhelming", rest until the pain returns to the initial rating.
4. Once pain returns to the initial rating, return to activity.
5. Repeat the above steps.



Helpful Hints:

1. Use a timer to remind yourself of the beginning and end of period of activity/inactivity.
2. Don't wait for the pain to get so bad that you **MUST** rest. Use your pain rating as a marker, not how much you achieved. Stop when the pain gets slightly worse, not when it is unbearable.
3. Plan in advance and break your tasks into smaller pieces instead of doing everything all at once.
4. Modify **HOW** you do something, (e.g., sitting vs. standing; fast vs. slow), not whether you will do something.

Sleep Hygiene:

A Guide To Sleeping Better

Sleep hygiene consists of several simple guidelines and aids which can, if practiced, help most of us get more restful and restorative sleep with greater daytime wakefulness. Practicing good sleep hygiene can improve sleep and reduce the need for sleep-inducing medications. Below are some common elements of good sleep hygiene.

Get the right amount of sleep for you. Sleep needs vary from person to person. Most people need about 8 hours of sleep, but some need six and some need nine. Find your best rest, and try to get this much sleep each night consistently. Keeping a "Sleep Diary" of your waking and sleeping schedule can help determine your most restful sleep period.

Try to sleep through the night. Try to minimize wakeups during the night. Numerous studies have shown that sleep is most restful and restorative when it is relatively continuous without periodic waking. Seven hours of continuous sleep beats nine hours of fitful sleep with periodic wakeups! To help get uninterrupted sleep: (a) decrease alcohol intake especially in the evening, (b) don't drink water just before going to bed (prevents nighttime waking to urinate), and (c) try to reduce anxiety and worrying just before going to bed.

Keep Regularly scheduled time for sleep. Try to work with your body's natural circadian rhythms - your internal "about a day" biological clock - as much as possible. For most people, it's best to sleep when the sun is down and be awake when the sun is up. It helps to go to sleep and wake up at the same time everyday - including the weekends! Calculate bedtimes around the required wakeup times for work, school, and other planned morning activities to get full rest.



Sleep Hygiene: (Continued)

Don't go to bed unless you are sleepy. Unfortunately, the old "lie in bed and sleep will eventually come" method is not very effective for most people. Spending more time in bed does not mean that sleep will eventually come sooner. It is not good to associate going to bed with lying there and not sleeping. If awake after twenty minutes or so, get out of bed and do something. Only go to bed when you are sleepy and ready for sleep.

To nap or not to nap, this is the question. For most people, naps disrupt the sleep-wake cycle and are not beneficial to good nighttime sleep. This is particularly true if the naps are in the evening. Studies suggest that most people should not nap. For insomniacs, irregular napping causes even more nighttime sleep problems. Insomniacs should not nap. Some individuals may benefit from naps, such as narcoleptics, shift workers, and others whose schedules won't allow for a full night's sleep. For many, a bit of exercise may be better than a nap to promote good nighttime sleep.

When you get up, stay up! When you wake up after a continuous sleep, don't try to snooze. Try to get up after waking and expose yourself to bright sunlight right after waking. This helps set a good sleep-wake routine. Again, try to maintain the same bedtime and wakeup times on the weekends as much as possible.

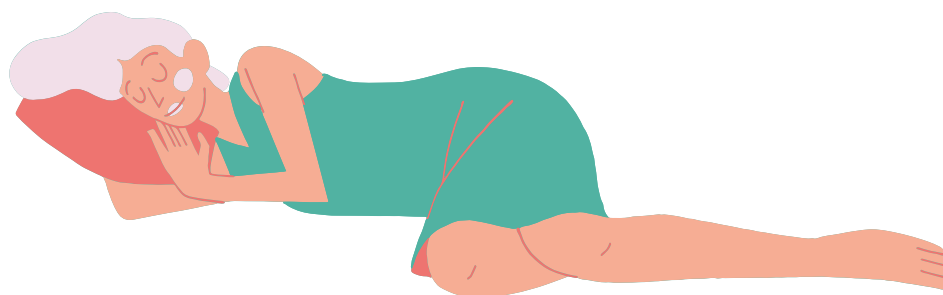
Use the bed for only sleeping, that other fun thing and maybe reading. The bed should be associated only with sleeping, sex, and possibly a very relaxing and sleep-promoting activity such as reading. Avoid watching TV in bed. If possible, remove the television from the bedroom. Refrain from activities such as paying bills, talking on the phone, or computer work in bed. If you read, be sure to turn off the reading light afterward.



Sleep Hygiene: (Continued)

Find the right bed and pillows. Despite the wonderful advertisements seen and heard about the latest magic bed and pillows, no one bed is best for everyone. There is no one best mattress for sleep. Different people have different preferences in mattresses and pillows. Make sure the mattress and pillows are comfortable for YOU. Replace any uncomfortable or worn-out mattresses. If you suffer from allergies, choose bedding that helps repel or deter common allergies.

Be cool. The body temperature rises during the day and cools during the nighttime. Most people sleep better when the bedroom is cool but not cold. Warm air temperature usually disrupts sleep. Sometimes taking a warm bath just before bedtime will help because the body cools afterward, and this cooling induces sleep. The purity and humidity of the air in the room is also essential. For some with allergies, air purifiers may help. For those who get dry throats during sleep, cool-mist humidifiers may help



Make it dark and uninterrupted. We should sleep in darkness and avoid light. Light signals our brain to wake up. Try to keep bedroom as dark as possible without lamps or night lights turned on during the night. Eyeshades or masks can be used if necessary. Most individuals sleep best in silence or with some monotonous "white" noise that screens out abrupt and interrupting sounds.

Defuse worries and obsessions before bedtime. Try to find methods of distracting yourself from daily concerns just before bedtime. This may help avoid the sleep disturbance that comes with anxiety and worrying.

Find a way to UNWIND and RELAX just before bedtime. Prayer, meditation, reading a novel, listening to quiet music, deep breathing exercises, and taking a warm bath can all work, depending on the person.

Sleep Hygiene: (Continued)

Exercise in the afternoon to sleep better. Routine exercise in the late afternoon is associated with better sleep patterns. After exercising in the late afternoon, the body temperature falls about five to six hours later, inducing sleepiness. Afternoon exercising is associated with higher levels of restorative deep sleep. The time to fall asleep is shortened with regular exercise. However, try to avoid exercising within three hours of sleeping as this can increase alertness and result in a raised body temperature at bedtime, which disrupts sleep.

See your doctor. Get effective treatment for diseases that cause sleep disruption. Many diseases and psychiatric problems associated with sleep disturbance are treatable. These include (a) heart disease, (b) diabetes, (c) thyroid disease, (d) psychiatric disorders such as depression and anxiety, (e) respiratory disorders like asthma and bronchitis, (f) gastroesophageal reflux disease or GERD, (g) musculoskeletal disorders like arthritis, and (h) neurological disorders. Getting effective treatment for these diseases can significantly improve sleep quality.



Food and sleep. Food and sleep. Make it light and early. Bedtime snacks and large, late dinners usually disrupt sleep. Blood flow and body temperature increase for digestion, which can interrupt the body cooling necessary for inducing the best sleep. It's also important not to go to bed hungry either, since this can disrupt sleep. Light dinner five to six hours before sleep is best for most people. Drinking before bed can also cause frequent wakeups to urinate. The choice of drinks also affects sleep. Alcohol induces sleep but then disrupts the cycles of sleep during the night. Caffeine is a stimulant that can disrupt sleep. Remember that the half-life of caffeine is about six hours, so caffeinated beverages should not be drunk after lunch. Sometimes warm milk or herbal teas like chamomile can help create a sedating effect that helps induce sleep.

Sleep Hygiene: (Continued)

Avoid foods that cause heartburn or GERD. Avoid foods that cause heartburn or GERD. Heartburn and gastroesophageal reflux disease disrupt sleep in many people. To circumvent this problem, try to avoid spicy foods, acidic foods (tomatoes, etc.), and fried foods for dinner or evening snacks. If necessary, use stomach acid reducers to lower the discomfort that can disrupt sleep. Raising the pillows or tilting the head of the bed upward (lowering the stomach in relation to the esophagus) can sometimes help. A sleep-diary can be used to find out which food is causing nighttime heartburn or GERD.

Alcohol is NOT a good sleep sedative. The most common drug used to induce sleep in Americans is alcohol. Unfortunately, while alcohol is a depressant drug and may induce sleep, it also markedly disrupts the cycles of sleep, resulting in more nighttime wakeups and non-restful sleep. For the most restful sleep, the general guideline is no alcohol within four hours of bedtime.

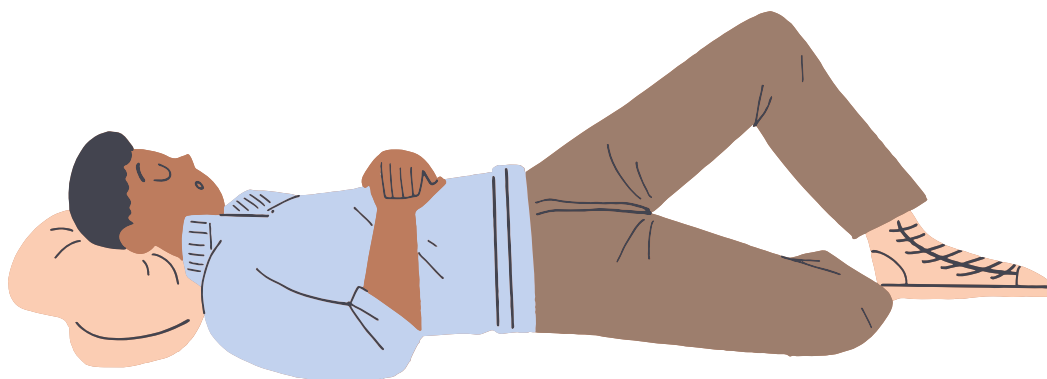
Avoid chronic use of sleep medications. Most sleep medications (prescribed or over the counter) should be used only temporarily. Most sleep drugs are not prescribed for periods longer than three weeks. Habituation, down-regulation, tolerance, and dependence are all associated with various types of sleep medications. In general, alcohol should be avoided when taking most sleep medications.



Sleep Hygiene: (Continued)

If you smoke or chew, try to quit. The nicotine contained in tobacco products is a powerful stimulant that disrupts sleep. When smokers sleep, they experience a powerful nicotine withdrawal syndrome that produces fast brain waves promoting wakefulness. Nicotine causes problems in both falling asleep and waking up. In several studies, smoking is also associated with increased nightmares, which can disrupt sleep. Quitting smoking usually results in temporary sleep disruption, but then sleep improves for the long term. If you do smoke, try not to smoke within four hours of bedtime. This will help produce a better night's sleep.

Find your bedtime ritual - and practice it! Most children are raised with certain bedtime rituals (brushing your teeth, saying prayers, going to the bathroom, etc.) that become associated with inducing sleep. However, many adults discard such rituals despite studies showing that individuals who routinely practice bedtime rituals sleep better. These rituals prepare the body and mind for sleep and should be cultivated and practiced throughout life. Just brushing your teeth and reading a book for a while before bedtime can do the trick.



If your sleep is disrupted, keep a sleep diary. Sleep diaries chart waking and nighttime behaviors systematically. Many of us are unaware of how our daily behaviors affect sleep. Patterns of sleep and waking shown in the diary can be useful in determining what may be disrupting our sleep as well as diagnosing sleep disorders. Diaries may vary for children, adults, and the elderly. Copies of such diaries are available from your physician and from sources such as the National Sleep Foundation.

Acceptance & Pain

What Does *Accepting* Chronic Pain Mean?

- Accepting chronic pain means learning to live despite the pain experience
- Accepting chronic pain means advocating for yourself and your health so that you can be as healthy as possible
- Accepting chronic pain means learning our limits and learning to cope with feelings of guilt when we have to say "no"
- Acceptance means having a willingness to have pain while actively choosing to keep living life
- Accepting chronic pain means being able to look at your diagnosis as something you have, not who you are. Your condition does not define you.
- Accepting chronic pain means re-evaluating your roles as husband/wife, mother/father, etc. as well as your life's goals - and figuring out how you can live a values-guided life and attain your goals with your chronic condition. Sometimes it may mean adapting your roles and goals.

Acceptance of Chronic Pain is Linked With:

Lower pain ratings
Lower depression ratings
Lower pain-related anxiety ratings
Increased physical and social activity
Less pain avoidance
Better work status



Myths About Chronic Pain:

- Accepting chronic pain does not mean giving in to it, and it doesn't mean that you stop looking for treatment (in moderation).
- Accepting chronic pain does not mean accepting a lifetime of suffering.
- Accepting chronic pain does not mean you are never allowed to feel angry or sad because of your pain.
- Accepting chronic pain does not mean that you have to give up hope for the future.
- Accepting chronic pain does not mean you are giving up fighting or choosing to be healthy

*[HTTPS://CONTEXTUALSCIENCE.ORG/SYSTEM/FILES/MCCRACKEN_L_M1998.PDF](https://contextualscience.org/system/files/MCCRACKEN_L_M1998.PDF)

The Spoon Theory

Adapted from www.butyoudontlooksick.com
By Christine Miserondino

My best friend and I were in the diner, talking. As usual, it was very late, and we were eating French fries with gravy. Like normal girls our age, we spent a lot of time in the diner while in college, and most of the time we spent talking about boys, music or trivial things, that seemed very important at the time. We never got serious about anything in particular and spent most of our time laughing.

As I went to take some of my medicine with a snack as I usually did, she watched me with an awkward kind of stare, instead of continuing the conversation. She then asked me out of the blue what it felt like to have Lupus and be sick. I was shocked not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. She had seen me cry in pain, what else was there to know?

I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I was a little surprised as being my roommate in college and friends for years, I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what it felt like, not physically, but what it felt like to be me, to be sick.

As I tried to gain my composure, I glanced around the table for help or guidance, or at least stall for time to think. I was trying to find the right words. How do I answer a question I never was able to answer for myself? How do I explain every detail of every day being affected and give the emotions a sick person goes through with clarity. I could have given up, cracked a joke like I usually do, and changed the subject, but I remember thinking if I do try to explain this, how could I ever expect her to understand. If I can't explain this to my best friend, how could I explain my world to anyone else? I had to try at least.

The Spoon Theory (Continued)

At that moment, the spoon theory was born. I quickly grabbed every spoon on the table. I grabbed spoons off of the other tables. I looked at her in the eyes and said, "Here you go, you have Lupus." She looked at me slightly confused, as anyone would when they being handed a bouquet of spoons. The cold metal spoons clanked in my hands as I grouped them together and shoved them into her hands.

I explained that the difference in being sick and being healthy is making choices, consciously thinking about things when the rest of the world doesn't have to. The healthy have the luxury of a life without choices, a gift most people take for granted.

Most people start the day with an unlimited amount of possibilities, and energy to do whatever they desire, especially young people. For the most part, they do not need to worry about the effects of their actions. So for my explanation, I used spoons to convey this point. I wanted something for her actually to hold, for me to then take away, since most people who get sick feel a "loss" of a life they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case, Lupus, being in control.

She grabbed the spoons with excitement. She didn't understand what I was doing, but she is always up for a good time, so I guess she thought I was cracking a joke of some kind like I usually do when talking about touchy topics. Little did she know how serious I would become.

I asked her to count her spoons. She asked why, and I explained that when you are healthy, you expect to have a never-ending supply of "spoons." But when you have to plan your day now, you need to know precisely how many "spoons" you have at the beginning. It doesn't guarantee that you might not lose some along the way, but at least it helps to know where you are starting. She counted out 12 spoons. She laughed and said she wanted more. I said no, and I knew right away that this little game would work when she looked disappointed, and we hadn't even started yet. I've wanted more "spoons" for years and haven't found a way yet to get more, why should she? I also told her she always had to be conscious of how many she had, and not to drop them because she can never forget she has Lupus.

The Spoon Theory (Continued)

I asked her to list off the tasks of her day, including the most simple. As she rattled off daily chores or just fun things to do, I explained how each one would cost her a spoon. When she jumped right into getting ready for work as her first task of the morning, I cut her off and took away a spoon. I practically jumped down her throat. I said, "No! You don't just get up. You have to crack open your eyes, and then realize you are late. You didn't sleep well the night before. You have to crawl out of bed, and then you have to make yourself something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today and tomorrow too." I quickly took away a spoon, and she realized she hasn't even gotten dressed yet.

Showering cost her spoon, just for washing her hair and shaving her legs. Reaching high and low that early in the morning could actually cost more than one spoon, but I figured I would give her a break; I didn't want to scare her right away. Getting dressed was worth another spoon. I stopped her and broke down every task to show her how every little detail needs to be examined. You cannot simply just throw clothes on when you are sick. I explained that I have to see what clothes I can physically put on; if my hands hurt that day, buttons are out of the question. If I have bruises that day, I need to wear long sleeves, and if I have a fever, I need a sweater to stay warm and so on. If my hair is falling out, I need to spend more time to look presentable, and then you need to factor in another 5 minutes for feeling bad that it took you 2 hours to do all this.

I think she was starting to understand when she theoretically didn't even get to work, and she had six spoons remaining. I then explained to her that she needed to choose the rest of her day wisely, since when your "spoons" are gone, they are gone. Sometimes you can borrow against tomorrow's "spoons," but just think how hard tomorrow will be with less "spoons." I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So you do not want to run low on "spoons." because you never know when you truly will need them. I didn't want to depress her, but I needed to be realistic, and unfortunately, being prepared for the worst is part of a real day for me.

The Spoon Theory (Continued)

We went through the rest of the day, and she slowly learned that skipping lunch would cost her a spoon, as well as standing on a train, or even typing at her computer too long. She was forced to make choices and think about things differently. Hypothetically, she had to choose not to run errands so that she could eat dinner that night.

When we got to the end of her pretend day, she said she was hungry. I summarized that she had to eat dinner, but she only had one spoon left. If she cooked, she wouldn't have enough energy to clean the pots. If she went out for dinner, she might be too tired to drive home safely. Then I also explained that I didn't even bother to add into this game, that she was so nauseous that cooking was probably out of the question from the start. So she decided to make soup, it was easy. I then said it is only 7 pm, you have the rest of the night but maybe end up with one spoon, so you can do something fun, or clean your apartment, or do chores, but you can't do it all.

I rarely see her emotional, so when I saw her upset, I knew maybe I was getting through to her. I didn't want my friend to be upset, but at the same time, I was happy to think that maybe someone understood me a little bit. She had tears in her eyes and asked quietly, "Christine, How do you do it? Do you really do this every day?" I explained that some days were worse than others; some days, I have more spoons than most. But I can never make it go away, and I can't forget about it, I always have to think about it. I handed her a spoon I had been holding in reserve. I said simply, "I have learned to live life with an extra spoon in my pocket, in reserve. You need always to be prepared."

It's hard. The hardest thing I ever had to learn is to slow down and not do everything. I fight this to this day. I hate feeling left out, having to choose to stay home, or not to get things done that I want to. I wanted her to feel that frustration. I wanted her to understand that everything everyone else does comes so easy, but for me, it is one hundred little jobs in one. I need to think about the weather, my temperature that day, and the whole day's plans before I can attack any one given thing. When other people can simply do something, I have to attack it and make a plan like I am strategizing a war. It is in that lifestyle, the difference between being sick and healthy. It is the beautiful ability not to think and just do. I miss that freedom. I miss never having to count "spoons."

The Spoon Theory (Continued)

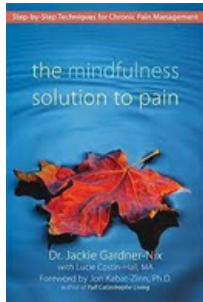
After we were emotional and talked about this for a little while longer, I sensed she was sad. Maybe she finally understood. Perhaps she realized that she never could truly and honestly say she understands. But at least now she might not complain so much when I can't go out for dinner some nights, or when I never seem to make it to her house, and she always has to drive to mine. I gave her a hug when we walked out of the diner. I had the one spoon in my hand, and I said, "Don't worry. I see this as a blessing. I have been forced to think about everything I do. Do you know how many spoons people waste every day? I don't have room for wasted time or wasted "spoons," and I chose to spend this time with you."

Ever since this night, I have used the spoon theory to explain my life to many people. In fact, my family and friends refer to spoons all the time. It has been a code word for what I can and cannot do. Once people understand the spoon theory, they seem to understand me better, but I also think they live their life a little differently, too. I think it isn't just good for understanding Lupus, but anyone dealing with any disability or illness. Hopefully, they don't take so much for granted or their life in general. I give a piece of myself in every sense of the word when I do anything. It has become an inside joke. I have become famous for saying to people jokingly that they should feel special when I spend time with them because they have one of my "spoons."



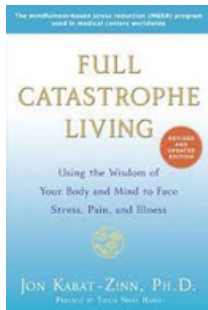
Resources for Chronic Pain (Continued)

Books



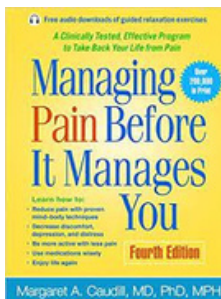
the mindfulness solution to pain

Gardner-Nix, J. (2009). New Harbinger Publications, Inc., Oakland, California



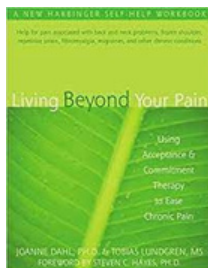
Full Catastrophe Living: Using the wisdom of your body and mind to face stress, pain and illness

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Managing Pain Before It Manages You

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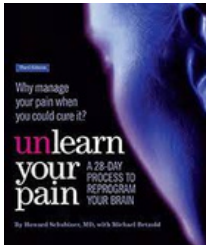


Living Beyond Your Pain: Using Acceptance and Commitment Therapy to Ease Chronic Pain

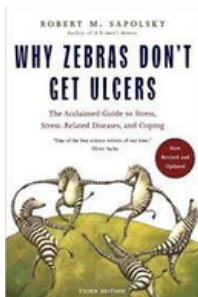
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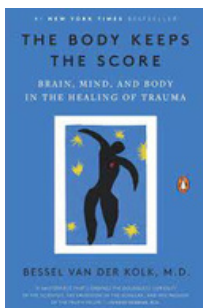
Books



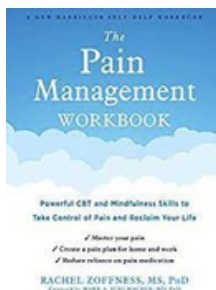
Unlearn your Pain: A 28-day Process to Reprogram your Brain
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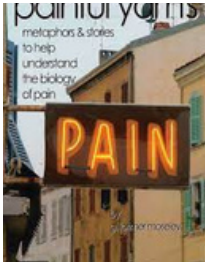
The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma Vand Der Kolk, B. (2014) Penguin Books



Pain Management Workbook (CBT)
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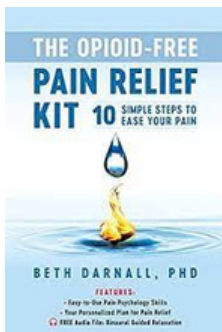
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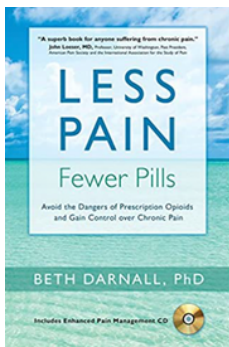
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Explain Pain Butler, D. (2013) NOI Group



The Opioid-Free Pain Relief Kit: 10 Simple Steps to Ease Your Pain Darnell, B. (2016). Bull Publishing



Less Pain, Fewer Pills. Darnell, B. (2014). Bull Publishing

Resources for Chronic Pain (Continued)

Smartphone Apps



Meditation & Mindfulness

1. Mindfulness Coach
2. Smiling Mind
3. Relax Melodies
4. Insight Timer
5. Calm
6. Tide
7. Down Dog Yoga

Pain Trackers

1. Curable
2. Journal of Pain

Other Pain Related Apps

1. CBT thought diary
2. Sleep Genius

Websites

American Chronic Pain Association (ACPA)

<http://www.theacpa.org/>

American Pain Foundation

<http://www.painfoundation.org/support/>

American Arthritis Foundation

www.arthritis.org

Partners Against Pain

<http://partnersagainstpain.com>

Fibrocenter

<http://www.fibrocenter.com>

Pain.com

<http://pain.com/>

Acupuncture of Indiana

<http://www.acupunctureofindiana.com/>

Indy Acupuncture

<http://www.indyacu.com/>

ACT & Mindfulness Meditations

http://www.portlandpsychotherapyclinic.com/counseling/mindfulness_and_acceptance_exercises

Unlearn your Pain

<https://www.unlearnyourpain.com>

Freedom from Chronic Pain

<https://www.freedomfromchronicpain.com>

Pain Self Assessment

When does it hurt?

Everyone's pain is different, but there are some common descriptions that sufferers often use. Answer the questionnaire below to further describe your pain.

How long does the pain usually last?

- ☐ Momentarily
- ☐ One or a few days at a time
- ☐ Persists all the time
- ☐ Other _____
- ☐ A few hours
- ☐ Weeks at a time

What makes it worse?

- ☐ Standing, bending or lifting
- ☐ Strenuous activity
- ☐ Inactivity
- ☐ Weather changes
- ☐ Other _____
- ☐ Touching or pressure
- ☐ Weight bearing
- ☐ Stress
- ☐ Poor cushioning

Is the pain worse when you wake up?

- ☐ Yes
- ☐ No
- ☐ Sometimes

Does the pain improve after you move around?

- ☐ Yes
- ☐ No
- ☐ Sometimes

Does it gets worse when you move around?

- ☐ Yes
- ☐ No
- ☐ Sometimes

Is there anything that makes it better?

- ☐ Rest or sleep
- ☐ Massage
- ☐ Coolness
- ☐ Creams or ointments
- ☐ Non-prescription medications (i.e., ibuprofen, acetaminophen)
- ☐ Other _____
- ☐ Exercise
- ☐ Heat
- ☐ Changing
- ☐ Herbal Remedies

Pain
is **inevitable.**
Suffering
is **OPTIONAL.**

