LIVING WELL WITH CHRONIC PAIN

A GUIDE TO PAIN MANAGEMENT



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What is Chronic Pain?

Pain is the body's warning signal that something is not right. When pain first appears, patients and their health care providers work together to see if they can identify and address the underlying cause and eliminate the pain. But for many, the pain associated with a condition, disease, or injury cannot be stopped. As time passes, these patients may be diagnosed with chronic pain. Treatment goals will then shift from resolving the pain to reducing and managing it.

Pain is typically considered chronic when it persists or recurs for longer than three months. In many cases, chronic pain can last for years or a lifetime. Often, chronic pain becomes the sole or predominant clinical problem for individuals, regardless of its origin. Some pain conditions can be diagnosed through testing, so depending on the patient's symptoms, diagnostic evaluation may be called for. But regardless of the cause of the pain, we do not yet know what makes acute pain become chronic nor the specific neurobiological mechanism(s) of pain in the human body.

Pain can be felt as:

- Burning
- Stabbing
- Aching
- Pulsing
- And many other sensations

These sensations can occur anywhere in the body. They can range from mild to severe, intermittent to continuous, and distracting to disabling. Chronic pain is considered a disease in and of itself, creating notable changes in the nervous system and brain.



It can be challenging to manage chronic pain effectively, especially when it is severe. There is no one-size-fits-all approach to treatment. Every person with pain responds differently to various therapies, even when they have the same condition or injury.

Working alongside health care providers, most people with pain will need to engage in a process of trial and error to find a treatment plan that works for them. The plan must be adjusted as the individual's health evolves. Typically, successful pain management requires a multidisciplinary, multimodal approach, combining therapies to improve quality of life and increase function.

It's important to note that chronic pain affects far more than physical health. The chronic pain experience encompasses physical or sensory, cognitive, emotional, and social aspects, affecting an individual's equilibrium and overall lived experience. Pain impacts all aspects of an individual's life, including their ability to work, engage in social or recreational activities, and even complete daily activities like showering or making a meal. Understandably, pain and its associated limitations can affect mental health as well, causing significant sadness, stress, fear, frustration, and anger. That's why multidisciplinary, comprehensive care addressing both the body and mind—is so important.

Chronic pain is challenging in many ways. But living a happy, fulfilling, and productive life is still possible—even with pain.

Be patient with yourself as you learn to cope, celebrate the small victories, and prioritize your health and well-being. Most importantly, remember: **You are not alone!**

Chronic Pain in America



- More than 51.6 million American adults (21% of the population) live with chronic pain.
- 17.1 million American adults live with high-impact chronic pain, or pain that frequently limits life or work activities.
- Pediatric chronic pain estimates range from 11% to 38% of children under 18.
- There are 52.4 new cases of chronic pain per 1,000 people each year—a higher rate than that of several other common health conditions, including diabetes, depression, and high blood pressure.

- About 83% of people with highimpact pain are unable to work.
- Chronic pain is the leading cause of long-term disability.
- Pain in America costs as much as \$635 billion yearly in direct health care costs, lost productivity, and disability payments.
- As of 2018, 96% of medical schools in the United States did not require students to take courses on pain medicine.
- People with chronic pain have at least twice the risk of suicide compared to those without chronic pain.

U.S. Pain regularly conducts surveys on critical topics in chronic pain. Check out the results at uspainfoundation.org/surveyreports.



Causes, Risk Factors, & Diagnosis

Causes & risk factors

Many factors can increase your risk of chronic pain. These factors can be environmental or biological and include:

- Genetics
- Age
- Being assigned female at birth
- · Having surgery
- Being overweight or obese
- Stress or mood disorders
- Previous trauma

The most common pain conditions are back pain, arthritis, and migraine and headache disorders. Still, there are hundreds of conditions that can cause long-term pain.

Diagnosis

Currently, there are no reliable tests that can objectively measure pain, although researchers are working to change that. In the meantime, clinicians typically rely on diagnostic tests to determine the cause of pain and identify an appropriate treatment strategy. Clinicians diagnosing these conditions also depend on the patient's description of their pain, which is why mutual respect, trust, and honesty are essential. The type of pain determines which diagnostic tools are appropriate.

Tests that can help determine or clarify the underlying cause of pain include:

- Bloodwork
- Imaging, such as MRIs, X-rays, CT scans, or ultrasounds
- Diagnostic injections
- Electromyography (used to assess muscle health and function)
- Nerve conduction testing (used to assess nerve health and function)
- Neurological assessments
- · Mobility and strength assessments
- Genetic testing



An Introduction to Pain Management

Each person with pain is unique; a treatment that works well for one individual may cause an adverse reaction for someone else. People with pain often go through a long process of trial and error to identify what works best for them. While it's easy to get frustrated when a certain therapy option doesn't work, **don't give up**—try something else.

Once you receive a chronic pain diagnosis or have lived with pain for more than six months, it's a good idea to get connected with a pain specialist. Primary care physicians can help manage pain, but ideally, a pain specialist will be involved in your treatment. While clinicians in specialties like neurology and orthopedics may also be able to offer some pain management options, it's important to have someone on your team who is an expert in pain itself. Whatever type of provider you see, as you begin to explore options for relief, remember that it is unlikely one treatment alone will adequately manage your pain. A multidisciplinary, multimodal approach that combines various treatments is typically the most effective.

For example, if medication, physical therapy, and injections all provided some measure of pain reduction, combining these treatments can lead to a greater overall decrease in pain—further leading to a significant, positive impact on quality of life and daily functioning.

If you are seeking a quality pain clinic or center, try to find one that emphasizes multidisciplinary care. In addition to pain management specialists, a good pain center will employ a range of providers—for example, psychologists or psychiatrists, clinical social workers, sleep medicine experts, nutritionists, and physical and occupational therapists. While an experienced pain specialist will have many suggestions for treatment, it's important to educate yourself on the various strategies and techniques available for pain relief, including self-management techniques. The list of treatment options starting on page nine is a great place to start.

Keep in mind, too, that researchers are always making headway in discovering new treatments. **Don't lose hope!**



When you are navigating the road to finding helpful treatments, the support and community from others who understand what it is like to live with pain can make the difference between persevering and giving up. Visit **painconnection.org** to join one of U.S. Pain's free peer support groups.



Tips for Pain Management

- **Start small.** If your pain levels allow it, start with low-risk, noninvasive treatment options, such as physical therapy and behavioral approaches like acceptance and commitment therapy, before moving to more invasive interventions. While medications, injections, and surgeries can be vital components of pain management, they come with risks and side effects. Especially when it comes to invasive procedures, always get a second opinion.
- Do your homework. Use the internet or your local library to research your condition and evidence-based treatments. Make sure to verify that the information is reliable. Government agencies, patient-led organizations, and well-known sites like WebMD and Healthline are typically good resources. Educating yourself is especially important if your condition is rare—your doctor may not have the time or resources to research the nuances of your disease.
- Get the most out of your doctors' visits. Bring a list of questions, and think carefully about what your goals are for your appointment. Don't be shy about speaking up for yourself and your needs. If possible, ask a family member or friend to come with you. They can help advocate for you, and having a second pair of ears to absorb all the information from your doctor or help take notes can be helpful.
- Stay organized. Dealing with complex health issues can be a part-time or even fulltime job in and of itself. Consider starting a binder or folder with everything in one place to help you juggle your appointment reminders, test results, therapy options, and insurance details. Remember, too, that you have the right to request your medical records and test results from any provider you see.

- Prioritize your mental health. Many people with pain are so busy trying to manage their physical health that they forget to take care of themselves emotionally. But chronic pain can affect your mood and stress levels, and in turn, your emotions and stress can impact your chronic pain. Talk to your care provider about ways to mitigate the emotional impact of pain, like connecting with a support group or an experienced pain psychologist or counselor.
- Be the squeaky wheel. Don't give up if your insurance company denies a treatment option or says a specialist is not in-network. Ask your clinician to help you appeal the decision, or appeal it yourself. In addition, many states have health advocacy offices that can help with insurance issues. Try reaching out to them for assistance if your appeal is unsuccessful.
- Look into specialized programs. Large medical centers and hospitals sometimes offer immersive inpatient or outpatient pain management programs. These programs can help jump-start your treatment plan and provide you with a variety of resources for managing pain. Program lengths may range from one to eight weeks.
- **Consider clinical trials.** If you have difficulty finding a treatment that works, consider joining a clinical trial. These research studies often give patients access to cuttingedge therapies unavailable to the general public. However, the newness of these treatment options makes it even more important to be aware of potential risks, side effects, and interactions with your other treatments.



Treatment Options

<u>Share this list with your clinician.</u> Talk to them about what options might make sense for your unique situation. As much as possible, start with low-risk, noninvasive options first, and always consider therapies in combination with one another.

Self-management techniques

- Activity modification or pacing
- · Assistive devices or technologies
- Diet and nutrition
- Movement
- Meditation and mindfulness
- Sleep hygiene (building habits that promote healthy, consistent sleep)
- Stress reduction techniques

Restorative therapies

- Bodywork (such as chiropractic care or trigger point therapy)
- Dry needling
- Exercise programs
- Flotation therapy
- Heat and cold therapy
- Kinesiology taping
- Massage therapy
- Occupational therapy
- Osteopathic medicine
- Physical therapy
- Pool or aquatic therapy
- Postural training
- Traction therapy

Complementary and integrative health options

- Acupressure
- Acupuncture
- Aromatherapy
- Art, music, dance, and equine therapy
- Ayurvedic medicine
- Craniosacral therapy
- Cupping
- Herbal and vitamin products
- Hypnosis
- Reflexology
- Reiki
- Tai Chi
- Traditional Chinese medicine
- Yoga



Treatment Options

Mind-body and behavioral health

approaches

Addressing the psychological and psychosocial impact of pain does not mean your pain isn't real. But stress exacerbates pain, and in turn, pain intensifies stress.

- Acceptance and commitment therapy
- Biofeedback or neurofeedback
- Cognitive behavioral therapy
- · Counseling and therapy
- Meditation and mindfulness
- Psychiatric care
- Spirituality
- Stress reduction techniques
- Support groups
- · Virtual reality programs and technologies

Medications

The medication categories below are associated with general pain relief; however, many other disease-specific medications treat the condition that may have led to chronic pain, and therefore, may help relieve some pain (e.g., calcitonin gene-related peptide inhibitors for migraine, or immunosuppressive medications for autoimmune disorders). Some pain medications may combine individual medicines from multiple categories below (e.g., acetaminophen plus hydrocodone, which is an opioid analgesic). Medications may be delivered in various ways—for example, orally, intravenously, or topically. Medications may be prescribed or available over the counter.

- Acetaminophen
- Antidepressants
- Antiepileptics
- Corticosteroids
- Local anesthetics and topicals
- Medical foods
- Muscle relaxants
- N-methyl-D-aspartate receptor antagonists

Medications

- N-type calcium channel blockers
- Nonsteroidal anti-inflammatory drugs (NSAIDS) such as ibuprofen or naproxen
- · Opioid agonists and antagonists
- Opioid analgesics

Cannabinoids

These products may include cannabidiol (CBD) or tetrahydrocannabinol (THC), also called medical cannabis. Less-common cannabinoids that are present in some products include cannabinol (CBN), cannabigerol (CBG), cannabichromene (CBC), Delta-8 THC, and Delta-9 THC; these products are still being researched regarding their effectiveness for pain. While CBD is federally legal, medical cannabis, Delta-8, and Delta-9 are not, and laws vary state by state. You should research the laws in your state and discuss these treatment options with your doctor. There are a variety of ways to administer these products for pain relief.

- Concentrates/extracts
- Edibles and pills
- Flower (eating raw buds)
- Oils
- Smoking and vaporizing
- Sublingual sprays
- Tinctures
- · Topicals and patches



Treatment Options

External neuromodulation and stimulation devices

- Deep oscillation therapy
- H-Wave electrical stimulation device
- High-frequency impulse therapy
- Infrared light therapy
- Interferential current stimulation
- Laser therapy
- Neuromuscular electrical stimulation
- Percutaneous electrical nerve stimulation
- Pulsed electromagnetic field therapy
- Scrambler therapy
- Transcutaneous electrical nerve stimulation
- Ultrasound therapy
- Vagus nerve stimulation



There is no easy fix for chronic pain. Yet there are a wide range of therapies and strategies that can help reduce its severity and its impact on your life. For a comprehensive list of these options and to help determine which might be right for your specific pain, visit our website, **mypainplan.org**, to access this list online and build a customized, printable pain plan.

Interventional Procedures

Injections, blocks, and infusions

- Epidural injections
- Facet blocks
- Hyaluronic acid injections
- Joint injections
- Ketamine, lidocaine, and other infusions
- Medial branch blocks
- OnabotulinumtoxinA injections
- · Peripheral nerve blocks
- · Platelet-rich plasma injections
- Stem cell therapy
- Sympathetic nerve blocks
- Trigger point injections

Neurolysis procedures

- · Chemical neurolysis
- Cryoneurolysis or cryoablation
- Radiofrequency ablation or lesioning

Implanted devices

- Dorsal root ganglion stimulation
- Intrathecal pain pump
- · Peripheral nerve and field stimulation
- Spinal cord stimulation

Surgeries and procedures

• There are many surgeries and procedures that may help treat various types of chronic pain. When less invasive treatment options have not helped, surgery may be a good option to discuss with your medical provider.

Self-Management Strategies

In conjunction with traditional pain management, self-management strategies can help reduce pain levels and their impact on your quality of life. Don't underestimate your ability to have an impact on your health.

Activity modification or pacing

Modifying or replacing your activities may seem obvious. Still, it can be difficult to adjust when you're used to being able to do things a certain way. It can take many years to fully understand your body's limitations and specific triggers for pain, and then to find strategies to work with or around them. Be patient with yourself as you explore your body's limits—and its capabilities.

Your individual needs will vary. Perhaps you need to lie down for 10 minutes every two hours. You may find you can go for a 30-minute walk, but you need to allow 30 minutes of rest before and afterward. Perhaps you need a standing desk instead of a seated one to work at your computer comfortably. As you get to know your body's new limitations, keep in mind there is a delicate balance between getting appropriate rest and recuperation and keeping up your strength, mobility, and stamina as much as possible.

Exercise

As difficult as it is to get yourself moving when you have chronic pain, getting started through some level of movement—no matter how small or limited—is important. Here are four key reasons to get moving:

• Strength, flexibility, and stamina. Chronic pain can negatively impact all three, which in turn increases your pain and level of disability.

- **Protecting the joints and organs.** Excess body weight puts strain on your joints, muscles, and organs.
- **Cardiovascular health.** Insufficient activity can result in disabling cardiovascular conditions, from orthostatic intolerance to heart disease.
- Endorphins. Aerobic exercise, or exercise that increases your heart rate, produces endorphins, the feel-good chemicals that decrease stress. Decreasing stress enables you to better cope with pain and can even help decrease pain itself.

Start small and increase the intensity of your workout as your body allows. Any movement or exercise, no matter how minimal, is better than nothing—do the best you can! Some examples of gentle exercise include yoga, tai chi, aquatic exercise, walking, and riding recumbent bikes. That said, check in with your health care provider before beginning any exercise program to ensure it is appropriate for you, and avoid exercise that increases your pain.

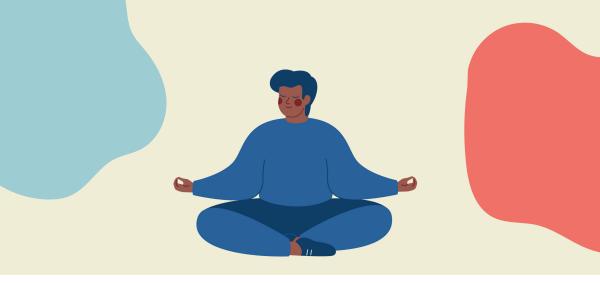
Sleep hygiene

An estimated 50% to 88% of people with chronic pain have ongoing sleep difficulties. Studies show that inadequate sleep can exacerbate pain, creating a difficult cycle to break. Here are some tips for getting a good night's rest despite pain.

• Establish a routine. Going to bed and waking up at the same time every day—even on the weekends underscores the natural sleep-wake cycle in your body. Help reinforce bedtime by establishing a wind-down routine. Consider meditating, reading, or listening to soothing music. In addition, you can encourage your natural circadian rhythms by making sure you get enough exposure to the sun during the day (which can include daylight bulbs or light therapy) and limiting exposure to light at night.

- Create a restful environment. Turn on white noise, use earplugs, invest in comfortable bedding, and keep the room temperature cool. Try to avoid using electronic devices (TV, smartphones, tablets) for at least 30 minutes before bedtime.
- Watch what you eat and drink. Caffeinated products, sugar, nicotine, or any other stimulants should be avoided for at least four to six hours before you plan to go to sleep. Even alcohol, which initially makes you feel tired, makes it harder to get highquality sleep.
- Limit naps. Napping during the day can interfere with sleep at night, so limit needed naps to 30 minutes and give yourself at least four hours between a nap and bedtime. In addition, even gentle exercise during the day helps tire out your body and can foster better sleep at night.

Still struggling? Ask your doctor about meeting with a sleep specialist.



Stress reduction

Pain increases stress, and stress increases pain. But you can break this cycle by proactively trying to reduce stress as much as possible. Reducing stress can, in turn, improve your ability to cope with the pain. It may even help ease the pain itself.

Some examples of stress reduction strategies and techniques include:

- Meditation
- Relaxation techniques such as breathing exercises, progressive muscle relaxation, visual/guided imagery, and mindfulness
- Music, art, or dance therapy
- Journaling
- Exercise
- Support groups
- Spirituality
- Counseling and therapy

Generally speaking, reducing stress with chronic pain also requires:

- Pacing yourself to allow for sufficient rest and recovery
- Learning to say no and putting your health first
- Focusing on the things you can do and not what you can't
- Communicating clearly with your loved ones about your needs and challenges
- Letting go of guilt and shame surrounding pain

For more advice on managing stress when you have pain, find a psychologist, therapist, or support group in your area.

Diet and nutrition

A balanced diet is vital to maintaining health and getting essential nutrients that support your overall well-being. Some people find that certain types of diets lessen their pain, such as an antiinflammatory diet, vegetarian or vegan diet, paleo diet, gluten-free diet, or others.

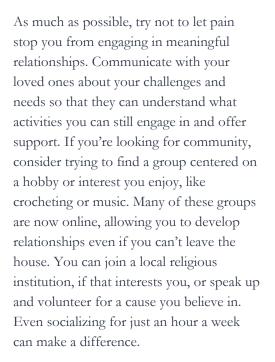
Regardless of whether you follow a specific set of guidelines surrounding food, here are some key dietary principles for general health:

- Eat as many vegetables and fruits as possible
- · Limit sugary and processed foods
- Avoid foods with trans fats and saturated fats
- Eat more foods that have "good" fats, like fish, avocados, nuts, and olive oil
- Stay hydrated

If you want extra help with your diet, consider meeting with a licensed dietician.

Social connection

People with pain often feel isolated and alone. Connecting with others is important, even though pain and resulting limitations —like being unable to drive or leave the house—can make that challenging.



Peer support can be particularly helpful. U.S. Pain Foundation offers free virtual peer support groups through its Pain Connection program. More information can be found at **painconnection.org**.

It's also easier than ever to find support groups online. You can use the web to find a support group dedicated specifically to people with your condition—even many rare diseases.



Emotional Well-Being

Chronic pain, especially severe pain, can have an enormous impact on your emotional health. Research has shown that people with pain are significantly more likely to experience anxiety, depression, and suicidal thoughts. Remember that you are not atypical, oversensitive, or weak for experiencing emotional distress because of pain.

This emotional distress is a normal, reasonable response to physical pain and its associated limitations.

Unfortunately, despite the widely recognized psychosocial effects of pain, caring for mental health often takes a backseat to treating physical symptoms. But mental health issues exacerbate chronic pain, and pain intensifies mental distress. This does not mean the pain is "all in your head." It simply means that the mind and body are linked. Taking care of your emotional well-being can help improve your pain—or, at the very least, help you better cope with it.

Strategies and treatments for mental health

Psychotherapy. General psychotherapy, or talk therapy, can be helpful in coping with pain. Many licensed professionals, including clinical psychologists, psychiatrists, therapists, counselors, and social workers, engage in psychotherapy. Be sure to find a licensed practitioner ideally with experience helping those with chronic health issues. Following are a few examples of more specific types of psychotherapy beneficial for people living with chronic pain.

Psychotherapy

- Cognitive behavioral therapy: Emphasizes awareness of negative thinking so you can respond to challenges in a more productive, thoughtful way.
- Acceptance and commitment therapy: Aims to enhance psychological flexibility by promoting acceptance of thoughts and emotions, fostering mindfulness, and encouraging commitment to valuesbased actions.
- Psychoanalytic or psychodynamic therapy: Explores unconscious feelings or thoughts and the impact of the past on the present.

Biofeedback therapy. During

biofeedback, you're connected to sensors that provide information about your body functions, like heart rate or breathing. This feedback helps you identify how subtle changes, such as relaxing muscles or focusing on your breath, can impact those functions to help impact pain, depression, or anxiety. A psychotherapist, occupational therapist, or physical therapist can offer biofeedback.

Psychiatric care. Psychiatric care involves the use of medical interventions—most commonly, medications—to treat mental health conditions. Psychiatric care should go hand-in-hand with other mental health strategies. There is research indicating a physiological connection between depression and chronic pain, and several antidepressants have been found to reduce chronic pain. Psychiatrists and psychiatric nurse practitioners also can diagnose mental health conditions, and some provide psychotherapy.

Peer support. It is enormously helpful to connect with others who understand what it's like to live with pain. Peer support groups often provide education and coping skills for chronic illness and come in many forms: in-person, online, and over the phone.

The U.S. Pain Foundation offers free monthly peer support group meetings online that provide compassionate support and evidence-based education to help people learn about pacing, resilience, coping, and more. The groups are peer-led and not a therapy group. To attend a meeting, visit painconnection.org/support-groups.



Meditation & mindfulness. Meditation and mindfulness are useful tools for coping with the emotional impact of pain. They can help improve your ability to tolerate pain without anxiety or fear, which can make the pain worse. Examples include focusing on your breath, visualization or guided imagery, body scanning or progressive relaxation, and practicing gratitude. There are many approaches and philosophies to explore. **Stress reduction techniques.** While meditation and mindfulness are useful stress reduction tools, there are a variety of other methods as well (also discussed in the previous section). These include aromatherapy, art or expressive therapy, journaling, exercise or stretching, spirituality, spending time in nature, and more. Find what works for you!

About U.S. Pain Foundation

The U.S. Pain Foundation is a national 501(c)(3) nonprofit organization. Our mission is to empower, educate, connect, and advocate for all individuals who live with a chronic illness or serious injury that causes pain, as well as their caregivers or care partners and clinicians.

We are deeply invested in helping individuals through our programs and services, which are all free to patients, their families, and their providers. These include:

- *INvisible Project* A print and online magazine sharing the personal stories of people living with chronic pain.
- State and Federal Advocacy We fight for change at the state and federal levels, advocating for direct and affordable access to individualized, multidisciplinary pain care.
- Pain Connection A national network of free online peer support groups. Trained volunteer peer leaders host state, national, daily, and specialized population meetings.

- **Pediatric Pain Warrior Program** -Serves children and their families through a family summer camp, indepth retreats, programming featuring expert speakers, and more.
- **Building Your Toolbox** A monthly educational series teaching individuals a pain management strategy or skill.
- **MyPainPlan.org** An interactive site allowing individuals to explore 85+ types of treatments and create a personalized list to discuss with medical providers.
- **Storybank** A tool to share your story online.
- Volunteer Network Raises awareness about chronic pain, offers education and resources, and advocates for change at all levels of government.
- Awareness Months Promote greater understanding of specific pain-related topics through activities, events, and initiatives during Pain Awareness Month in September and KNOWvember in November.

Learn more at uspainfoundation.org.

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