

A close-up photograph of a person's arm and hand. The person is wearing a blue long-sleeved shirt. Their right hand is gripping their left forearm, suggesting they are holding their arm due to pain. The background is dark and out of focus, with some bokeh light effects. The text 'Living Well with Chronic Pain' is overlaid on the image, with 'Living Well' in a blue and orange box and 'with Chronic Pain' in white text below it. The U.S. Pain Foundation logo is in the bottom right corner.

Living

Well

with  
Chronic  
Pain



U.S. PAIN  
FOUNDATION

# Living Well with Chronic Pain

An educational guide



**2** What is Chronic Pain?

**4** Causes, Risk Factors, & Diagnosis

**6** Pain Management

**8** Treatment Options



**10** Self-Management Strategies

**14** Emotional Well-Being

**16** About U.S. Pain Foundation

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# What is Chronic Pain?

**P**ain is the body's warning signal that something is not right. When painful symptoms first arise, patients and their health care providers work together to see if they can identify and address the underlying cause. For many conditions and injuries, however, there is no precise medical or surgical cure. As time passes, in addition to other diagnoses or even without an identifiable cause, patients may be diagnosed with chronic pain. Treatment goals will then shift from resolving the pain to reducing and managing it.

Typically, pain is considered chronic

when it persists for six months or more. But for some patients, chronic pain can last for years or even a lifetime. There are many possible causes for long-term pain, including injury, such as involvement in a car accident, or underlying disorders or diseases, like fibromyalgia or arthritis.

The type of pain experienced can be as varied as the reasons behind it. Pain can be felt as burning, stabbing, aching, pulsing, and many other sensations. These sensations can occur anywhere in the body, and can range from mild to severe, from intermittent to continuous, and from distracting to disabling. Over time,

chronic pain can become a disease in and of itself, creating notable changes in the body, particularly the nervous system.

Because each individual person with pain is so unique, it can be challenging to manage pain effectively. There is no one-size-fits-all approach to treatment, and pain management is usually aimed at reducing pain, not eliminating it. 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. Typically, successful pain management requires finding a combination of multidisciplinary, multimodal therapies that reduce pain enough to improve quality of life and increase function.

It's important to note that chronic pain affects far more than physical health. In fact, it can impact all aspects of an individual's life, including their ability to work, to engage in social or recreational activities, and even to complete basic activities, like showering or making a meal. Understandably, pain and its associated limitations can cause significant sadness, stress, fear, frustration, and anger. That's why comprehensive care—that addresses both the body and mind—is so important.

Chronic pain is challenging in many ways. But it is still possible to live a happy, fulfilling, productive life, even with severe 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

- **50 million** American adults, or **20 percent** of the population, live with chronic pain.
- Estimates of pediatric chronic pain range from **5 to 38 percent** of all children.
- **20 million** adults live with high-impact pain, or pain that frequently limits life or work activities.
- About **83 percent** of people with high-impact pain are unable to work.
- Chronic pain is the **leading cause** of long-term disability.
- Pain costs between **\$500 and \$635 billion** each year in terms of health care costs, lost productivity, and disability payments.
- Veterinary students receive **five times** as many education hours on pain management as medical students.
- For every **10,000 people** with severe pain, there is **only one** board-certified pain specialist.
- The National Institutes of Health spends **less than 2 percent** of its funding on pain research.
- Patients receive an average of **30 percent** pain reduction from treatment.
- People with pain are **more likely** to experience depression, anxiety, and suicidal thoughts.

**Chronic pain is challenging in many ways. But it is still possible to live a happy, fulfilling, productive life, even with severe pain.**





# Causes, Risk Factors, & Diagnosis

## CAUSES & RISK FACTORS

There are many factors that can increase your risk of chronic pain. These factors can be environmental or biological, and include:

- Genetics
- Increased age
- Being female
- Having surgery
- Being overweight or obese
- Stress or mood disorders
- Previous trauma

Chronic pain is typically caused by an injury or a separate, underlying health condition. The most common pain conditions are back pain, arthritis, and migraine and headache disorders, but 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 the pain, if possible, and to identify appropriate treatment.

Clinicians also rely on the patient's report of his or her pain for diagnosis, which is why mutual respect, trust, and candor is essential.

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

- Bloodwork
- Imaging, such as MRI, X-rays, CT scans, ultrasound
- 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

Accurate diagnosis is vital to effective treatment. Your type of pain will usually determine which diagnostic tools are right for you.



# Pain Management

**E**ach person with pain is entirely unique: a treatment that works well for one individual may cause a negative 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. Most likely, something else will help—you just have to keep looking.

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. While clinicians in specialties like neurology and orthopedics may be able to offer some pain management options, it's important to have someone on your team who is an expert in pain itself. Primary care physicians can also help manage pain, but ideally, a pain specialist would be involved in the treatment plan.

Whatever type of provider you see, as you begin to explore relief options, remember that it is unlikely one therapy alone will adequately manage your pain. A multidisciplinary, multimodal approach that combines

various treatments is typically most effective. For example, even if medication reduces your pain by 20 percent, physical therapy by 20 percent, and injections by 10 percent—when combined, these treatments represent a 50 percent overall decrease in pain, which can have a significant, positive impact on quality of life and daily functioning.

If you are able to get to a pain clinic or center, try to find one that emphasizes multidisciplinary care. A good indicator is when the center employs a range of specialists in addition to traditional pain doctors—for example, psychologists, clinical social workers, sleep medicine experts, nutritionists, and/or physical therapists.

While an experienced pain specialist will have a lot of suggestions for treatment, it's important to educate yourself on the various strategies and techniques available for pain relief. The list of treatment options in the next section is a great place to start. Keep in mind, too, that researchers are always making headway in discovering new treatments. Don't lose hope!

## TIPS FOR PAIN MANAGEMENT

**Start small.** If your pain levels allow it, start with low-risk, noninvasive treatment options, like physical therapy and cognitive behavioral therapy, before moving to more serious 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, consider getting a second opinion.

**Do your homework.** Use the internet or your local library to research your condition and evidence-based treatments. Try 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—even with the best intentions, your doctor may not have the time or resources to research the nuances of your disease.

**Maximize your doctors' visits.** Bring a list of questions, and think carefully about what your goals are for your appointment. Don't be afraid to advocate 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 can be helpful.

**Stay organized.** Dealing with complex health issues can be a part- or even full-time job in and of itself. To help juggle your various appointments, test results, therapy options, and insurance issues, consider starting a binder or folder with everything in one place. 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 likewise, your mood and stress levels can affect your chronic pain. Talk to your care provider about ways to mitigate the emotional impact of pain, like connecting with a support group or experienced counselor.

**Be the squeaky wheel.** If your insurance company denies a treatment option or says a specialist is not in-network, don't give up! 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.

**Specialized programs.** Large medical centers and hospitals sometimes offer immersive pain management programs on an inpatient or outpatient basis. These programs can help give you a jump-start on your pain management and provide you with a variety of resources for managing pain. Programs may last for a week, while others may be an entire month or longer.

**Consider clinical trials.** If you are having a difficult time finding a treatment that works, consider finding a clinical trial. These research studies often provide patients with access to cutting-edge therapies that are not available to the general public. Like with any treatment, they may have risks and side effects to consider.

# Treatment Options

Share this list with your clinician. 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. Please keep in mind this is not a conclusive list.

## SELF-MANAGEMENT STRATEGIES

- Activity restriction or modification
- Assistive devices or technologies
- Diet and nutrition
- Exercise and strengthening programs
- Meditation and mindfulness
- Sleep hygiene
- Support groups
- Stress reduction techniques, including visualization or body scanning
- Stretching and mobility programs

## RESTORATIVE THERAPIES

- Chiropractic care
- Decompression (traction units, tilt tables)
- Hot & cold therapy
- Massage
- Occupational therapy
- Physical therapy
- Pool or aquatic therapy
- Postural training

- Strength training
- Taping (kinesiology tape)
- Stretching and strengthening programs, like Pilates, yoga, or tai chi

## MIND-BODY APPROACHES

*A note about mind-body approaches: Addressing the psychosocial impact of pain does not mean your pain isn't real. But stress exacerbates pain, and likewise, pain exacerbates stress. Interrupting this cycle is essential to improving your quality of life.*

- Acceptance and commitment therapy
- Biofeedback or neurofeedback
- Cognitive behavioral therapy
- Group therapy
- Meditation and mindfulness
- Psychiatric care
- Stress reduction techniques
- Support groups
- Talk therapy
- Virtual reality technology

## COMPLEMENTARY & ALTERNATIVE MEDICINE

- Acupuncture or acupressure
- Aromatherapy
- Art, music, or dance therapy

- Color therapy
- Cupping
- Craniosacral therapy
- Dry needling
- Floatation therapy
- Herbal and vitamin supplements
- Hypnosis
- Reiki
- Reflexology

## MEDICATIONS

*The medication categories below are associated with general pain relief; however, there are many other disease-specific medications that treat the underlying condition and therefore relieve pain (e.g. calcitonin gene-related peptide inhibitors for migraine, or immunosuppressive medications for autoimmune disorders). Some pain medications may work across multiple channels and categories of relief, or they may be formulated in combination with other medications to target multiple channels. Medications may be delivered in various ways; for example, orally, intravenously, or topically.*

### Nonopioid analgesics

- Acetaminophen
- Nonsteroidal anti-inflammatory (NSAID) medications
- Salicylates
- COX-II inhibitors

### Opioid analgesics

#### Adjuvant analgesics

- Antiepileptic medications
- Antidepressants
- Local anesthetics and topicals

### Other pain relievers

- Benzodiazepines
- Corticosteroids
- GABA<sub>B</sub> receptor agonists
- Medical cannabis
- Muscle relaxants
- N-methyl-d-aspartate (NMDA) receptor antagonists
- N-type calcium channel blocker
- Opioid agonists and antagonists

## NONINVASIVE INTERVENTIONS & DEVICES

- Cold laser
- Deep oscillation therapy
- Electrical nerve stimulation
- External trigeminal nerve stimulation
- Functional electrical stimulation
- High-frequency impulse therapy
- Infrared light therapy
- Interferential current stimulation
- Neuromuscular electrical stimulation
- Percutaneous electrical nerve stimulation
- Percutaneous neuromodulation therapy
- Peripheral nerve field stimulator
- Pulsed electromagnetic field therapy
- Scrambler therapy
- Transcutaneous electrical nerve stimulation (TENS)
- Ultrasound therapy
- Vagus nerve stimulation
- Other electric stimulation therapies

## INVASIVE INTERVENTIONS & PROCEDURES

### Injections or blocks

- Botulinum toxin injections
- Chemical sympathectomy
- Cryoneurolysis or cryoablation
- Corticosteroid injections
- Epidural injections
- Nerve, facet, & medial branch blocks
- Neurolysis or ablative techniques
- Radiofrequency ablation/lesioning (also known as rhizotomy)
- Thermal intradiscal procedures (e.g. intervertebral disc annuloplasty or transdiscal biaculoplasty)
- Trigger point injections

### Regenerative therapies

- Platelet-rich plasma therapy
- Prolotherapy
- Stem cell therapy

### Implanted pain devices

- Intrathecal pain pump
- Spinal cord stimulator implant or peripheral nerve field stimulation





# Self-Management Strategies

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

## ACTIVITY RESTRICTION OR MODIFICATION

Restricting or modifying your activities may seem obvious, but it can be difficult to adjust when you're used to being able to do certain things a certain way. It can take many years of trial and error to identify 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 abilities.

You will need to determine what your limitations are, but perhaps it's that you need to lie down for 10 minutes every two hours. Or maybe you 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, keep in mind there is a fine balance between getting appropriate rest and recuperation—and keeping up your strength, mobility, and stamina as much as possible.

Don't be afraid to get creative with accommodating your body's needs. Investigate assistive devices, like braces



or mobility tools, such as canes. Consider adaptive technology, too. For example, if typing on a computer is challenging, you may want to look into dictation software.

Occupational therapists can be very helpful in coming up with solutions for keeping up with your daily activities and continuing to do the things you enjoy. If you work, ask your manager about getting an assessment from an ergonomics specialist. Remember that you have a right to reasonable accommodations for your health in the workplace.

## DIET AND NUTRITION

A balanced diet is key to maintaining a healthy weight and getting important nutrients that support your overall well-being. Some people find that certain types of diets lessen their pain, such as an anti-inflammatory diet; a vegetarian or vegan diet; a paleo diet; a gluten-free diet; and so on.

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

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

If you're interested in extra help with your diet, consider meeting with a licensed dietician.

## EXERCISE

As difficult as it is to get yourself moving when you have chronic pain, it's also extremely important. Here are four key reasons to exercise however much your pain allows:

### 1. Strength, flexibility, and stamina.

Chronic pain can negatively impact your strength, flexibility, and stamina, which in turn increase your pain and level of disability.

### 2. Maintaining a healthy weight.

Excess body weight puts strain on your joints, muscles, and organs.

**3. Cardiovascular health.** Too little activity can result in disabling cardiovascular conditions, from orthostatic intolerance to heart disease.

**4. Endorphins.** Aerobic exercise 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 exercise, no matter how minimal, is better than nothing at all; just do the best you can. Some examples of gentle exercise include yoga; tai chi; aquatic exercise; walking; and reclining bikes. That said, be sure to check in with your health care provider before beginning any exercise program to ensure it is safe for you.



## SOCIAL CONNECTION

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

As much as possible, try not to let pain stop you from engaging in meaningful relationships. Communicate with your loved ones about your challenges and needs, so that they can try to offer support and understand what activities you can still engage in. If you don't have close friends or family, consider trying to find a group centered on a hobby, like crocheting or hiking; join a local religious institution, if that interests you; or look into volunteering.

Even if you can only socialize for an hour a week, that's great!

In particular, peer support groups with people who understand what you are going through can be very helpful. Try to locate a support group in your area. U.S. Pain Foundation offers in-person support groups through its program, Pain Connection, along with conference call support groups several times each month. More information can be found at [www.painconnection.org](http://www.painconnection.org).

Thanks to the internet, it's also easier than ever to find support groups online. Oftentimes, you can use the web to find a support group dedicated specifically to people with your condition—even rare diseases.

If you don't have a support group in your area or can't find one online, consider starting one!

## SLEEP HYGIENE

An estimated 50 to 80 percent of people with chronic pain have ongoing sleep difficulties. Studies show that inadequate sleep, however, can exacerbate pain. Here are some tips for ensuring you get 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—reinforces the natural sleep-wake cycle in your body. You can also help reinforce bedtime by establishing a wind-down routine, e.g. by meditating, reading, or listening to soothing music.

- **Create a restful environment.** Turn on white noise, use ear plugs, invest in comfortable bedding, and keep the room temperature cool. Help support your natural circadian rhythms by getting enough exposure to sun during the day and limiting exposure to light at night.

- **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 high-quality sleep.

- **Get tired!** Napping during the day can interfere with sleep at night. If you must, limit your snooze to 30 minutes, and give yourself at least four hours between the 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 reduce 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

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, counselor, or support group in your area.

**Don't underestimate your ability to have an impact on your health and pain levels.**





# Emotional Well-Being

**C**hronic 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. These are normal, reasonable responses to physical suffering 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 stress levels exacerbate chronic pain, and chronic pain

exacerbates stress levels. 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 cope with your pain.

## Strategies and treatments for mental health

• **Psychotherapy.** General psychotherapy, or talk therapy, can be helpful to coping with pain. There is a wide range of licensed professionals that engage in psychotherapy, including clinical psychologists, psychiatrists, counselors, and social workers. Be sure to find a licensed practitioner, ideally with experience

helping those with chronic health issues. Here are a few examples of more specific types of psychotherapy:

• **Cognitive behavioral therapy.**

This type of therapy emphasizes awareness of inaccurate or negative thinking, so you can respond to challenges in a more productive, thoughtful way.

• **Acceptance and commitment therapy.** This approach helps you come to terms with the reality of a challenging situation and refocus your energy on only the things you can proactively control or change.

• **Psychoanalytic or psychodynamic therapy.** This school of thought explores unconscious feelings/thoughts and the impact of the past on the present. It is one of the more traditional approaches to therapy.

• **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. Biofeedback can be offered by a psychotherapist or a physical therapist.

• **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.

• **Peer support.** As discussed in the previous section, connecting with others who understand what it’s like to live with pain is hugely helpful. Peer support groups often provide education and coping skills for chronic illness and come in many forms: in person, online, and over the phone. U.S. Pain Foundation currently offers peer support in person and over the phone through its program, Pain Connection. More information is available at [www.painconnection.org](http://www.painconnection.org).

• **Meditation & mindfulness.**

Meditation and mindfulness are useful tools for coping with the emotional impact of pain. On a basic level, these techniques can offer a distraction or escape from painful symptoms. But they can also help improve your ability to tolerate pain without anxiety or fear, which can make the pain worse. Examples of meditation and mindfulness 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.**

Stress reduction is not limited to meditation and mindfulness. Other techniques (also discussed in the previous section), include: aromatherapy; art or expressive therapy; journaling; exercise or stretching programs; spirituality; spending time in nature; and more. Find what works for you!

# About U.S. Pain Foundation



Established in 2011, U.S. Pain Foundation is the leading organization for people with chronic pain. Our mission is to empower, educate, connect, and advocate for individuals who live with chronic conditions that cause pain, as well as their caregivers and clinicians.

We offer numerous free programs and services, including:

- Pain Connection, a network of support groups
- INvisible Project, a magazine and display featuring patient stories
- Advocacy Program, which fights for pain warriors at the legislative level
- Pediatric Pain Warrior Program, which offers weekend retreats and more for kids and families
- Pain Education Portal (PEP) Talks, an educational webinar series
- Ambassador Network, a community of volunteers working to raise awareness

**And more!**

To learn more about U.S. Pain Foundation or get involved, visit [www.uspainfoundation.org](http://www.uspainfoundation.org) or call 800.910.2462.

*Johnson & Johnson*

*The U.S. Pain Foundation would like to thank Johnson & Johnson for supporting the Living Well with Chronic Pain booklet. We thank you for understanding the importance of educating and empowering individuals living with chronic pain.*



