



American Pain Foundation

A United Voice of Hope and Power over Pain



**Pain
Resource
Guide:**

Getting the Help You Need



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ABOUT THE AMERICAN PAIN FOUNDATION

Founded in 1997, the American Pain Foundation (APF) is the nation's leading independent non-profit 501(c)3 organization serving people with pain. Our mission is to improve the quality of life for people with pain by:

- Raising public awareness
- Providing practical information, education and support
- Advocating to remove barriers and increase access to effective pain management
- Promoting research



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For more information, call our toll-free message line at



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HOW TO USE THIS GUIDE



This booklet is designed to help you **take charge of your pain care**. It provides important information about pain and tips to assist you in getting the quality pain care you deserve. Whether you've just started experiencing pain or have lived with it for years, we hope this booklet will help you find answers to some of your most pressing questions.

Also included are downloadable pages to help you keep track of appointments with your healthcare provider(s) and record how you feel on a day-to-day basis. Be sure to refer to "Common Pain Terms" at the back of this booklet, which may be useful in talking with your health care team, family and friends about pain and pain management.



There you will find information about the causes of pain, treatment options, how to search for trained specialists, peer support and resources to help you cope with pain. Our web site also provides links to more than 200 carefully selected web sites on pain and related topics.

**READ THIS
BOOKLET TO
FIND OUT:**

- Why pain management is important
- How to find effective pain care and pain specialists
- Methods used to assess and diagnose pain
- Important treatment goals and an overview of available treatment options
- Questions to ask your healthcare provider
- Steps to reclaim your life
- Tips to overcome your fears and talk with loved ones

Pain affects more than 76 million Americans and can be an isolating experience.



THE PAIN PROBLEM

Pain is a critical, biological warning sign. It alerts the body when something is wrong, and can signal injury (for example, if you touch a hot oven or step on broken glass) or an underlying disease or infection (for example, cancer or shingles). Most people experience pain, whether it's from a nagging headache, a recent operation, or a broken bone. Pain can be classified as acute or chronic. Acute pain usually follows surgery or injury and resolves as the body heals itself. Pain is chronic when it persists after healing has taken place.

TYPES OF PAIN

Acute – occurs suddenly due to illness, injury or surgery. It has a short duration, which subsides when the injured tissue heals.

Chronic – pain that persists for long periods of time (usually ≥ 3 months). Failure to treat acute pain promptly and appropriately at the time of injury, during initial medical and surgical care, and at the time of transition to community-based care, contributes to the development of chronic pain syndromes. In such cases, pain signals remain active in the nervous system for weeks, months or even years.

Even though there have been exciting advances in medicine to help manage most pain, it is too often untreated, undertreated or improperly treated. This is a source of growing public health concern in America and has propelled APF and other groups to issue a call for improved pain management.

PAIN IN AMERICA: A SNAPSHOT



- More than 76 million Americans suffer with chronic pain; this doesn't account for those with acute pain from injury or surgery.
- Pain is the #1 reason for unscheduled doctor visits and the leading cause of disability.
- 3 out of 4 people do not receive adequate pain management.

For more Pain Facts & Figures, visit APF's Newsroom at www.painfoundation.org.

When uncontrolled, pain can wreak havoc on a person's life, dramatically reducing overall quality of life and interfering with relationships. When your ability to function is limited, you may become less productive at work and home. You may also find yourself avoiding hobbies and other activities that normally bring you happiness in order to prevent further injury or pain. Chronic pain can cause you to lose your appetite, feel weak and/or depressed. Depression is very common among people with pain and can actually worsen pain sensations. If you think you are depressed, seek help.

Beyond the human suffering, undertreated pain drives up the cost of healthcare, extending the length of stays in hospitals, increasing emergency room visits and leading to unplanned clinic visits.

CONSEQUENCES OF UNTREATED PAIN

Pain can aggravate other health problems, slow recovery and cause damage to the body. If untreated, pain can have serious physiological, psychological and social consequences, which may include:

- Weakened immune system and slower recovery from disease or injury
- Decreased quality of life. Pain adversely impacts almost every aspect of a person's life including sleep, work, socializing with friends and family and accomplishing everyday tasks.
- Human suffering, fear, anger
- Depression and/or anxiety
- Deterioration of relationships, marriages, intimacy
- Loss of independence (can't perform activities of daily living like dressing, being able to go to the grocery store, etc.)
- Loss of self-esteem

Many people with pain wrongly believe that pain is just something they have to live with—an inevitable part of their disease or condition, or a natural part of growing older. ***The fact is most pain can be relieved with proper pain management.***

There are a growing number of resources and treatments available to help people effectively manage pain and reclaim their lives. When pain is sufficiently controlled, stress is reduced and the body heals faster. Those who take an active role in their pain management tend to get these results: less pain and more involvement in and enjoyment of life.

So take action!

PAIN should **NEVER BE IGNORED.** It should be assessed thoroughly and **TREATED EARLY** and aggressively. This is the best way to minimize the suffering and disability often associated with undertreated pain.

FINDING A PAIN CARE PROVIDER



If you suffer with chronic pain, there's a good chance you've been going from one healthcare provider to another looking for relief. You may have been told, "Nothing more can be done to ease your pain," or "You'll just have to live with it." If this is true, you should take the time to find a healthcare provider who has the education, skills and willingness to work with you to manage your pain.

ESSENTIAL QUALITIES TO LOOK FOR IN A PROVIDER

Make sure you find a healthcare provider who you feel comfortable with who also:

- Knows about chronic pain and how to treat it.
- Believes your report of pain.
- Listens carefully to your concerns.
- Asks you questions and performs diagnostic tests to help identify the problem.
- Encourages you to ask questions.
- Is comfortable when you disagree.
- Is willing to speak to your family or friends if you are not feeling well.
- Works with you to develop a pain management plan that helps reduce your pain and sets realistic goals in order for you to regain important activities and skills.
- Provides information about risks and benefits of each pain treatment that is recommended.
- Tells you when he or she does not know something about your pain problem or treatment.

Although your family healthcare provider is trained to know about a wide range of diseases, he/she may not have had much training in treating pain. If your current treatment is not working or if your pain is getting worse, it's probably time to see a pain specialist. Pain specialists may include, but are not limited to:

- Anesthesiologists
- Neurologists
- Orthopaedic and Neurosurgeons
- Physical medicine and rehabilitation specialists (Physiatrists)
- Psychiatrists or psychologists



Does your healthcare provider listen to you? Is he or she able to assess and treat your pain? If after a reasonable time the answer is “no,” ask for a referral to a pain specialist, or find another healthcare provider. Remember this is your right.

FINDING A PAIN SPECIALIST

Start by asking your provider to refer you to a specialist with expertise in treating your particular problem. You may want to ask: “Who would you go to if you were in pain?” If he or she cannot suggest a specialist, the next step would be to check with your health insurance carrier to see if there are pain specialists or pain clinics in your area that are covered by your plan.

You can also look for pain specialists by:

- Asking friends, family members, co-workers—particularly those who’ve had pain or know someone with pain—for suggestions.
- Speaking with people who belong to pain support groups in your area or region. Ask which doctors they like and what they look for in a specialist or pain center.
- Contacting the referral service of the largest hospital in your area.
- Contacting your local chapter of the American Society of Pain Management Nurses (ASPMN) or the American Academy of Pain Medicine (AAPM).
- Researching your State Pain Initiative at <http://aspi.wisc.edu/state.htm>.
- Calling your state or county medical societies.
- Calling your local hospice. They can be helpful in finding a pain specialist even for non-end-of-life pain care.

See additional **Resources** on page 23 of this booklet for more information.



QUESTIONS TO ASK IF YOU ARE CONSIDERING CHANGING PROVIDERS

- Does the doctor treat my type of pain?
- Is he or she accepting new patients?
- How long will I have to wait to get an appointment?
- Does the practice/clinic accept my insurance?
- Are there nurses or physician assistants on staff and are they available to talk with me?
- Who will see me in the event of an emergency?

NO PAIN SPECIALISTS IN YOUR AREA?

- Call or write your chamber of commerce and/or contact the board of directors (chairman or members) of your local hospital. Ask about a larger hospital offering outreach clinics or visiting physicians.
- Contact your local legislators about the lack of resources in your area and request their assistance.

To verify a healthcare provider's credentials or to file a complaint, contact your State's Medical Board.



Set realistic expectations for pain relief. Persistent pain tends not to disappear. Look for a provider who will work with you to get you to the point where you can "live life again."

If you are someone who lives with pain, it's important for you to seek appropriate and timely care and social support.

PROTECTING YOUR HEALTH COVERAGE

Having health insurance is very important. Below are tips about your health coverage and ways to stay covered:

- Don't let your coverage end or lapse when you change jobs.
- Find out about COBRA eligibility if you lose, leave or change jobs. This is a federal law that allows former employees to keep health coverage through their company health plan for a limited time.
- Ask your employer about the Family and Medical Leave Act (FMLA) if you need to take an extended leave of absence. Under the FMLA, you may be able to receive up to 12 unpaid weeks off and your job will be protected.
- Find out whether you qualify for Medicare and/or Medicaid.
- Look into "high risk" pools that are sponsored by many states to provide health coverage to people who are considered medically uninsurable.
- Research prescription assistance programs (PAPs) and other discount programs offered by pharmaceutical companies to provide free or low cost prescription drugs to those who qualify. For more information, contact the Partnership for Prescription Assistance at 1-888-4PPA-NOW or www.pparx.org, or TogetherRx Access at 1-800-250-2839 or www.TogetherRxAccess.com.

If you have limited or no health insurance, you may want to contact:

- Your local hospital's social services department or your local health department.
- Patient Advocate Foundation at 1-800-532-5274 or www.patientadvocate.org.





DIAGNOSING PAIN PROBLEMS

Most hospitals, nursing homes, and other healthcare facilities are now required to assess and treat pain.

To correctly diagnose your pain, your healthcare provider may:

- Perform a complete physical exam
- Complete a pain assessment
- Ask detailed questions about your medical history and lifestyle
- Order blood work, X-rays and other tests

Note: Because of the current state of medical science and limited pain research, there are some causes of pain which may not be able to be confirmed with current medical technology and diagnostic tests. Just because a concrete cause for your pain can't be found, doesn't mean that your pain doesn't exist.

It's important for your healthcare provider to have a complete picture of your pain history. He/she may ask about seven characteristics of pain to help **LOCATE** your pain and make the correct diagnosis:

- L** the exact **Location** of the pain and whether it travels to other body parts.
- O** **Other** associated symptoms such as nausea, numbness, or weakness.
- C** the **Character** of the pain, whether it's throbbing, sharp, dull, or burning.
- A** **Aggravating** and **Alleviating** factors. What makes the pain better or worse?
- T** the **Timing** of the pain, how long it lasts, is it constant or intermittent?
- E** the **Environment** where the pain occurs, for example, while working or at home.

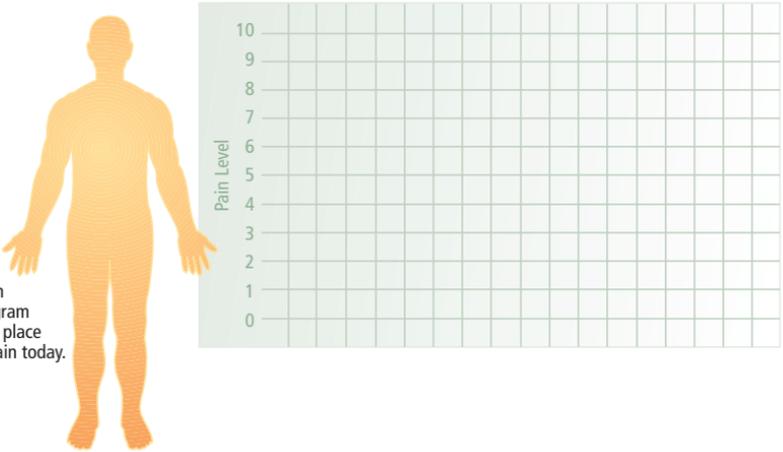
Pain scales are additional tools to help you describe the intensity of your pain and help your doctor or other healthcare providers diagnose or measure your level of pain. These include numeric, verbal and visual scales.

With **numerical scales**, you use numbers from 0-10 (0 being no pain and 10 being the worst pain ever) to rate the intensity of your pain.

Verbal scales contain commonly used words such as “mild,” “moderate” and “severe” to help you describe the severity of your pain.

Visual scales use aids like pictures of facial expressions, colors or gaming objects such as poker chips to help explain the severity of your pain. One type, the Wong Baker Faces Pain Rating Scale, shows six different facial expressions from happy (no hurt) to agony (hurts worst) to help you show your healthcare provider how much pain you feel. Body diagrams may also be used to help pinpoint where your pain occurs.

Put an “X” on the body diagram to show each place you’ve had pain today.



The image shows an orange silhouette of a human body on the left. To its right is a grid for rating pain level. The grid has 10 rows, numbered 0 to 10 from bottom to top. The vertical axis is labeled 'Pain Level'.



The Wong Baker Faces Pain Rating Scale consists of six faces in a row, each with a different expression and a corresponding number and description below it:

- 0 NO HURT (Happy face)
- 1 HURTS LITTLE BIT (Slightly smiling face)
- 2 HURTS LITTLE MORE (Neutral face)
- 3 HURTS EVEN MORE (Frowning face)
- 4 HURTS WHOLE LOT (Crying face)
- 5 HURTS WORST (Agony face)

Be aware of how you are feeling each day and take note of what makes your pain worse or better.

You may want to keep a log of activities or exercises you did and how each impacted your pain—pay attention to times when you have no pain, too. Follow your pain level throughout the day choosing several times that fit your routine, like when you get in or out of bed, eat certain foods, take medicines, go to the grocery store or go for a walk. It's also important to tell your provider how you are dealing and coping with pain. Are you more or less inclined to make social plans? Do you worry that you will have a flare up of pain when you travel? Do you have a support network to lean on?

Be an informed consumer and learn all you can about pain and pain management options.

Take your time when describing the intensity of your pain and how it interferes with your daily life and functioning. For example, you may notice that when your pain level is low, you can get out for a walk, but when it's high, you may not even make it out the door.

Is your pain affecting your sleep, mood, appetite and/or activity levels?

If so, consider starting a pain journal. APF's Target Pain Notebook is an easy-to-use tool to help you keep a record of your pain (when it occurs, for how long, the level or type of pain, etc.), its impact on day-to-day life (what activities you can and cannot do), response to various treatments over time, improvements in daily function and side effects. It can also help guide discussions with your healthcare provider. Keeping track of what things make your pain better or worse will help your healthcare team find the best ways to treat your pain.



To order your Notebook, visit www.painfoundation.org or call the toll-free message line at 1-888-615-7246.

HELPFUL HINTS ON YOUR ROAD TO PAIN RELIEF

It's important to become your own best advocate as you navigate the road to pain relief and reclaim your life. And the earlier you seek treatment, the better.

HERE ARE SOME OTHER HELPFUL THINGS TO KEEP IN MIND ALONG THE WAY:

- **Don't be afraid to speak up!** Only you know the extent of your pain and how it affects your quality of life.
- **Knowledge is power.** There are a variety of drug and non-drug therapies (e.g., physical therapy, yoga, meditation) available to effectively control pain; these are typically used in combination. Ask your healthcare provider about ways to relax and cope with pain. Your pain may feel worse if you are stressed, depressed or anxious.
- **Set realistic goals** with your healthcare provider for things you most want to do, such as sleeping, working, exercising or enjoying sexual relations. Begin with the easiest goals first.
- **Tell your provider** what over-the-counter medications, vitamins and supplements you take, at what dose and how often. Also let him or her know about other personal health habits (e.g., smoking tobacco, alcohol use), which can interfere with some pain treatments and increase pain levels.
- **Keep a pain journal** to record the frequency and intensity of your pain. Use descriptive words, such as sharp, crushing, throbbing, shooting or tender. Also, take note of how well your treatment plan is working and what makes your pain worse or better.
- **Write down questions** you have before each appointment, and tell your providers if there is something you don't understand.
- **Bring a relative or friend to your appointments** for support and to help take notes and remember what was said.
- **Find out about support groups** and educational programs in your area or online.
- **Reach out to supportive friends and family members** when you need them.
- **Know there will be good and bad days.**



TAKE ACTION: TREATING YOUR PAIN

Pain is complex and unique to each individual. There are many causes, and recommended treatment options are often different for individual patients. Successful pain management aims to:

- 1 Lessen the pain
- 2 Improve functioning
- 3 Enhance overall quality of life

Your pain management team will work with you to map out a treatment plan tailored to your specific needs. In doing so, they will consider many aspects of your pain and daily life, including:

- Type of pain (whether it is acute or chronic)
- Intensity of your pain
- Your physical condition, coping ability and challenges
- Your lifestyle and preferences for treatment

Common Pain Treatments

There are many ways to treat pain. Find out about the benefits and risks of drug and non-drug therapies. Learn about the different ways drugs can be prescribed. For example, opioids—strong medications for relieving serious pain—can be delivered through pills, a transdermal patch, or a pump. Many non-drug therapies, used alone or in combination with medications, can also help reduce pain. A few include relaxation therapy, exercise, psychological counseling, acupuncture and physical therapy, the application of cold or heat, as well as a host of complementary and alternative treatments, such as massage, acupuncture, and yoga.



YOUR TREATMENT PLAN WILL LIKELY INCLUDE A COMBINATION OF THE FOLLOWING (ALSO CALLED A MULTI-MODAL APPROACH):

- Pharmacotherapy (e.g., non-opioids, opioids and other medications)
- Psychosocial Interventions (e.g., stress management, coping, counseling)
- Rehabilitation Techniques (e.g., re-conditioning, exercise therapy, application of heat or cold, myofascial therapy)
- Complementary and Alternative Medicine (e.g., meditation, tai chi, dietary supplements, aromatherapy, therapeutic massage)
- Injection and Infusion Therapies (e.g., nerve blocks, patient-controlled analgesia, or PCA)
- Implantable Devices and Surgical Interventions (e.g., pumps, stimulators)



For detailed information about specific therapies within each of these treatment areas, visit the American Pain Foundation's web site, www.painfoundation.org, to download or order *Treatment Options: A Guide for People Living with Pain*.

APF'S ONLINE CLINICAL TRIALS RESOURCE CENTER

Clinical trials are changing the way diseases and associated pain is treated. These research studies aim to improve the effectiveness of available treatments and patients' overall quality of life. APF's web site features a searchable database of pain-related clinical trials offered through CenterWatch. Visitors can find information about trials, recent FDA drug and device approvals, new medical therapy trial results, research headlines and more.



SETTING THE RECORD STRAIGHT ON ADDICTION

Many people living with pain and even some healthcare providers believe that opioid medications are addictive. The truth is that when properly prescribed by a healthcare professional and taken as directed, these medications give relief. Physical dependence—which is not addiction—may occur and cause withdrawal symptoms if you stop taking these medications suddenly. For this reason, you need to go off your pain medications gradually with the guidance of your healthcare provider when/if stopping or lowering your pain medication dose is recommended. Be sure to talk with your healthcare provider before starting or stopping any medications.

Tolerance, physical dependence and addiction are not the same.

Tolerance refers to the situation in which a drug becomes less effective over time.

Physical Dependence means that a person will develop symptoms and signs of withdrawal (e.g., sweating, rapid heart rate, nausea, diarrhea, goosebumps, anxiety) if the drug is suddenly stopped or the dose is lowered too quickly.

Addiction refers to a condition when a person has lost control over use of the drug and continues to use it even when the drug is doing them or others harm. People who are addicted engage in unacceptable behaviors like obtaining pain medications from non-medical sources or altering oral formulations of opioids.

Unless you have a past or current history of substance abuse, the chance of addiction is very low when these medications are prescribed by a doctor and taken as directed. Still, those who suffer with chronic pain and a substance abuse problem (addictive disease) deserve the same quality of pain treatment as others.

**Make sure you understand the plan and carry it out fully.
If you don't, you are less likely to get relief.**



SAFELY STORING AND TAKING YOUR MEDICATION

Medications play an important role in the treatment of pain. Many different medicines can be used to help relieve pain. A few, such as aspirin, ibuprofen and acetaminophen, can be purchased in a pharmacy or supermarket without a prescription, but most pain relievers are only available with a prescription from your healthcare provider.

KEEP THE FOLLOWING POINTS IN MIND:

- **Pain medications work best if taken before the pain becomes severe.** You should take these medications as soon as you begin to feel uncomfortable. Once pain becomes severe, it takes more time and more medication to bring it under control. If your pain worsens, talk with your healthcare provider. He or she may safely prescribe higher doses or change the prescription. Non-drug therapies, such as relaxation training can also help give you relief.
- **Learn all you can about your prescribed medications.** Ask your healthcare provider why a particular medicine was chosen to manage your pain problem. Find out exactly how you should take your pain medicine, including the dosage (how much) and frequency (how often).
- **Give your healthcare provider a list of all the medications you are currently taking—both prescriptions and OTCs.** Include vitamins and herbal supplements as they can interact with medications and cause side effects or complications. In some cases, combinations of medications can either reduce or increase the effects of other needed medications.
- **Talk to your healthcare provider about any food or medication allergies you may have.** This information can help determine your treatment.
- **Take all medications as directed.** Even common, over-the-counter medications can have side effects—particularly if not taken as directed. Talk to your pharmacist about your medications and how different foods, drinks or supplements might interfere with how they work. For example, grapefruit juice has been shown to interfere with the action of many medicines.

- **Contact your healthcare provider if you experience any side effects from your medicine.** Side effects may be indicative of other problems or a need to adjust dosages. Nausea, drowsiness, itching and most other side effects caused by morphine and similar opioid medications usually last only a few days and can be managed. Many patients will tell you about the unfortunate trade-off between pain medicines and constipation and other bowel problems. It's important to manage constipation just as aggressively as it is to manage your pain. Talk to your provider about maintaining a good diet, one that's rich in fiber and low in fat, and find out whether he/she recommends using laxatives. Also be sure to drink plenty of water to stay hydrated.
- **Safely store your medications.** Separate prescription pain medications from vitamins, aspirin and other over-the-counter medications to avoid confusion. Keep medicines in a cool, dry place (not the bathroom medicine cabinet, which tends to be warm and humid), in the original bottle and out of a child's reach. Check with your pharmacist for specific storage instructions and never use a medication that has changed color, consistency, or odor, regardless of the expiration date.
- **Keep your prescription pain relievers in a secured location.** Opioids can be harmful if they aren't taken as prescribed. According to law enforcement reports, theft of personal supplies of pain medications, particularly opioids and other controlled substances, have occurred. Teens, family, friends or other visitors have taken medicines from home medicine cabinets, bedside tables or countertops where there is easy access. Others have been stolen from purses, briefcases and office desks. Consider your prescription pain relievers (and written prescriptions) as you would other valuables.
 - Keep them out of sight—a locked combination box, drawer or cabinet is ideal.
 - Let at least one trusted person know where to find them in case of emergency.
 - Do not carry your full supply with you unless traveling for a long period of time; ask your pharmacist for a smaller pill bottle for travel.
 - Do not lock them in your car.
 - Report any thefts immediately. Ask for a police report to share with your healthcare provider and placement in your medical record.

If your pain medication is stolen, you may not be able to get early refills. Keep them safe!

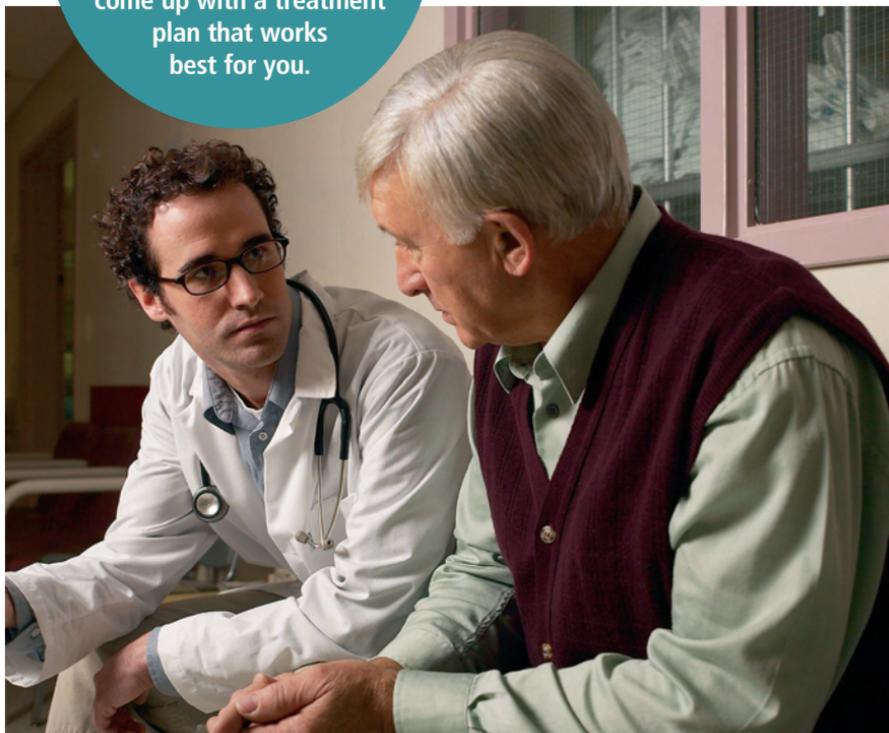
Caution: alcohol, in combination with many pain medications, can be very dangerous. If you drink, even socially, let your healthcare provider know.

For more information about safe medication use and storage, visit the National Council on Patient Information and Education (NCPIE) web site at www.bemedwise.org.

REMEMBER TO TELL YOUR HEALTHCARE PROVIDER ABOUT PAST TREATMENTS FOR PAIN

Have you taken prescription medication or had surgery? Tried massage? Applied heat or cold? Exercised? Taken over-the-counter medications or vitamin supplements?

Remember, **YOU** are part of your health care team, so play an active role in your pain care and work with your healthcare providers to come up with a treatment plan that works best for you.



No one should have to suffer **needlessly** when the knowledge and ability to manage most pain is available. Once your pain is **under control**, you'll be able to sleep better, focus on work, enjoy relationships with family and friends, and take part in social activities.

TALKING TO YOUR HEALTHCARE PROVIDER



It's important to talk openly with your healthcare provider about your symptoms and medical history, including previous treatments you've tried. To make the best use of your appointments, make a list of questions ahead of time (See page 18 for a sample log to help record what was said). You should also ask for copies of any lab tests results, so you can file these with your health records. Stay organized so you can stay on top of your health care.

Questions to Ask

Chances are you will have questions about your treatment. Here are some questions you may want to ask:

- **Have you** treated others with my type of pain?
- **What could** be causing my pain symptoms?
- **What options** would you recommend for treating my pain (medications and other non-drug therapies)?
- **What medications** work best for this type of pain?
- **How long** will it take for the medication to work?
- **How should** I store my medicine?
- **Do I need** to take this medicine with food?
- **What are** common side effects of this treatment?
- **What can** I do to ease the side effects?
- **How might** pain medications impact dietary supplements and medications I'm already taking?
- **What should** I do if I have breakthrough pain while taking this medication?
- **What other** non-drug therapies or activities should I consider to relieve my pain?
- **How much** relief should I expect from treatment?
- **When** can I expect to see some improvement?
- **Do you** work with specialists who can offer complementary therapies, such as acupuncture, massage or hypnosis?
- **What are** realistic expectations for pain relief given my condition?
- **Are there** activities I should temporarily or permanently avoid/engage in more often?
- **Who** do I call when I have a pain emergency?





Use this form to write down questions or concerns you have for your healthcare provider. Use the space provided to take notes that you can refer to later. Go to **www.painfoundation.org** to download additional copies. Notes pages are also included at the back of this booklet.

Appointment with: _____
(Provider Name)

Date: _____

Primary Reason(s) for Visit: _____

List of questions/concerns:

1. _____

Answer: _____

2. _____

Answer: _____

3. _____

Answer: _____

4. _____

Answer: _____

RECLAIMING YOUR LIFE: GETTING THE SUPPORT YOU NEED



Although pain can, at times, be debilitating, it's important to surround yourself with peers, friends and family. Talk openly about how pain is impacting your day-to-day life and ways they can help you to cope. You may want to identify someone you trust who can serve as your co-advocate. This is a person who can accompany you to health care visits and represent your concerns. Your co-advocate can be extremely helpful, particularly at times when your energy is low.

Because pain is subjective, many people struggle with the need to try to convince healthcare providers, friends and family about the existence and extent of their pain. The lack of direct and objective pain measures or laboratory tests fuel the need to justify the pain experience. This can lead to greater feelings of isolation. Take the time to tell loved ones what you are going through and don't let anyone tell you your pain is "just in your head." Share information and reading materials about your condition with your family and caregivers, and encourage them to ask questions.

Finding good pain care and taking control of your pain can be hard work, but there are a number of resources you can turn to for support, including PainAid, APF's online support forum featuring 10 live chats a week, more than 200 message boards. APF also offers other outlets for people to express and share their pain experience including *Voices of People with Pain* and *Creativity & Pain*.



For more information, visit our web site at
www.painfoundation.org.

There are a number of effective strategies for coping with pain, which include:

- Relaxation training – slow, deep breathing to release tension and relieve pain.
- Imagery – allows you to concentrate on pleasant scenes, events or sounds.
- Distraction techniques – helps you focus your attention away from negative thoughts whether it's listening to your favorite music, going out with a friend or reading a magazine.



OTHER ACTIVITIES THAT MIGHT HELP:

- **Go for a walk** in the neighborhood. Exchange a smile, pleasantries about the weather or a simple “Hi” can help boost your mood.
- **Create vacation destinations** in your mind and “visit” these spots throughout the day.
- **Watch a movie** either at home or the cinema. Always best enjoyed with someone. Comedies that make you laugh actually help your body produce pain-fighting and mood-boosting chemicals.
- **Take up a hobby**, such as knitting, arts and crafts or computer games.
- **Reach out to a friend** by phone, letter or e-mail and talk about something other than pain.
- **Spend time with your pet.** Dogs and cats give unconditional love. They need care and feeding and help establish a routine. They’re also a source of endless wonder and entertainment.
- **Learn something new.** Take an online course. Try a new craft or skill. This can help you focus on something other than your pain. Attending a class in person will help expand your social network.
- **Make a list** of things you need help with and refer to it when people offer assistance. Things like making meals and then freezing and labeling them in single portions, rearranging your living space in a way that helps you get around, shopping or cleaning.



STEER CLEAR OF ISOLATION AND DEPRESSION

If there are days you feel anxious or depressed, you are not alone. But there are things you can do to try to beat the blues.

- Decide that you will manage your pain rather than it managing you.
- Surround yourself with supportive loved ones who are willing to advocate for your health and well being.
- Talk openly with family and friends about the extent and impact your pain has on your life and provide them with educational materials and useful web sites when appropriate..
- Give concrete examples of ways caregivers can help you get the care you need and combat episodes of pain.
- Recognize your fears and work to overcome them. Don't let pain overshadow you.
- Continue to engage in activities you enjoy even if you need to cancel or cut back some days.
- Join *PainAid* and other peer support programs to share your experience with those who have been through it.



COMMON PAIN TERMS

Acute pain – occurs suddenly due to illness, injury or surgery. It has a short duration, which subsides when the injured tissue heals.

Addiction – refers to a medical diagnosis and is defined as a primary, chronic, neurobiological disease, with genetic, psychosocial, and environmental factors influencing its development and expression. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.

Breakthrough pain – pain that flares up or emerges through the comfort state obtained from drug and/or non-drug pain relief methods.

CAM – complementary and alternative medicine.

Chronic pain – pain lasting longer than expected healing time, may last for many months, years or a lifetime, may be constant or in intervals; cause may be unknown or result of recent or previous acute pain episode; may be related to another chronic disorder, such as arthritis, peripheral vascular disease, diabetes, or cancer.

Opioids – commonly prescribed medications due to their effective analgesic, or pain-relieving, properties.

Neuropathic pain – pain started or caused from alteration of the nervous system.

Nociceptive pain – another term used to describe acute pain as a response to a noxious (unpleasant) stimulus activating nerve cells to send pain signals along the nervous system for recognition and response. The nervous system is working appropriately.

Pain flares (flare ups) – pain that suddenly erupts or emerges with or without an aggravating event or activity.

Pain scales – tools that can help you describe the intensity of your pain and help your doctor or other healthcare providers diagnose or measure your level of pain. Three types of scales are commonly used: numeric, verbal and visual.

Physical dependence – means that a person will develop symptoms and signs of withdrawal if the drug is suddenly stopped or the dose is lowered too quickly. Physical dependence is normal; any patient who is taking an opioid on a regular basis for a few days should be assumed to be physically dependent.

Tolerance – refers to the situation in which a drug becomes less effective over time.

Withdrawal – symptoms of withdrawal occur when a drug is reduced or stopped. These include sweating, rapid heart rate, nausea, diarrhea, goosebumps, anxiety and insomnia, among others.

American Pain Foundation

www.painfoundation.org
1-888-615-PAIN (7246)

FIND A PAIN SPECIALIST

American Academy of Family Physicians

www.familydoctor.org

American Academy of Nurse Practitioners

www.aanp.org
202-966-6414

American Academy of Pain Management

www.aapainmanage.org
209-533-9744

American Academy of Pain Medicine

www.painmed.org
847-375-4731

American Academy of Physician Assistants

www.aapa.org
703-836-2272

American Board of Pain Medicine

www.abpm.org
847-375-4726

American Medical Association

www.ama-assn.org
312-464-5000

Case Management Resource Guide

www.cmrg.com
800-784-2332

Commission on Accreditation of Rehabilitation Facilities

www.carf.org
520-325-1044

Mayo Clinic Pain Management Center

www.mayoclinic.com

National Hospice and Palliative Care Organization

www.nhpco.org
703-837-1500

National Pain Foundation

www.nationalpainfoundation.org

Pain.com

www.pain.com/painclinics/default.cfm

FIND A COMPLEMENTARY & ALTERNATIVE MEDICINE (CAM) SPECIALIST

American Academy of Medical Acupuncture

www.medicalacupuncture.org
323-937-5514

American Association for Naturopathic Physicians

www.naturopathic.org
866-538-2267

American Association of Oriental Medicine

www.aaom.org
866-455-7999

American Chiropractic Association

www.amerchiro.org
703-276-8800

American Holistic Health Association

www.ahha.org
714-779-6152

American Massage Therapy Association

www.amtamassage.org
877-905-2700

American Osteopathic Association

www.osteopathic.org
800-621-1773

American Physical Therapy Association

www.apta.org
703-684-APTA (2782)

FIND A SUPPORT GROUP

American Chronic Pain Association

www.theacpa.org
800-533-3231

Caring Connections

www.caringinfo.org
800-658-8898

Family Caregiver Alliance

www.caregiver.org
800-445-8106

Friends' Health Connection

www.friendshealthconnection.org
800-48-FRIEND (483-7436)

National Chronic Pain Society

http://ncps-cpr.net
281-357-4673

National Family Caregivers Association

www.thefamilycaregiver.org
800-896-3650

PainAid

www.painfoundation.org

Pain Connection

www.pain-connection.org
301-309-2444

Well Spouse Association

www.wellspouse.org
800-838-0879

This is just a sampling of available resources. For more information, visit www.painfoundation.org.

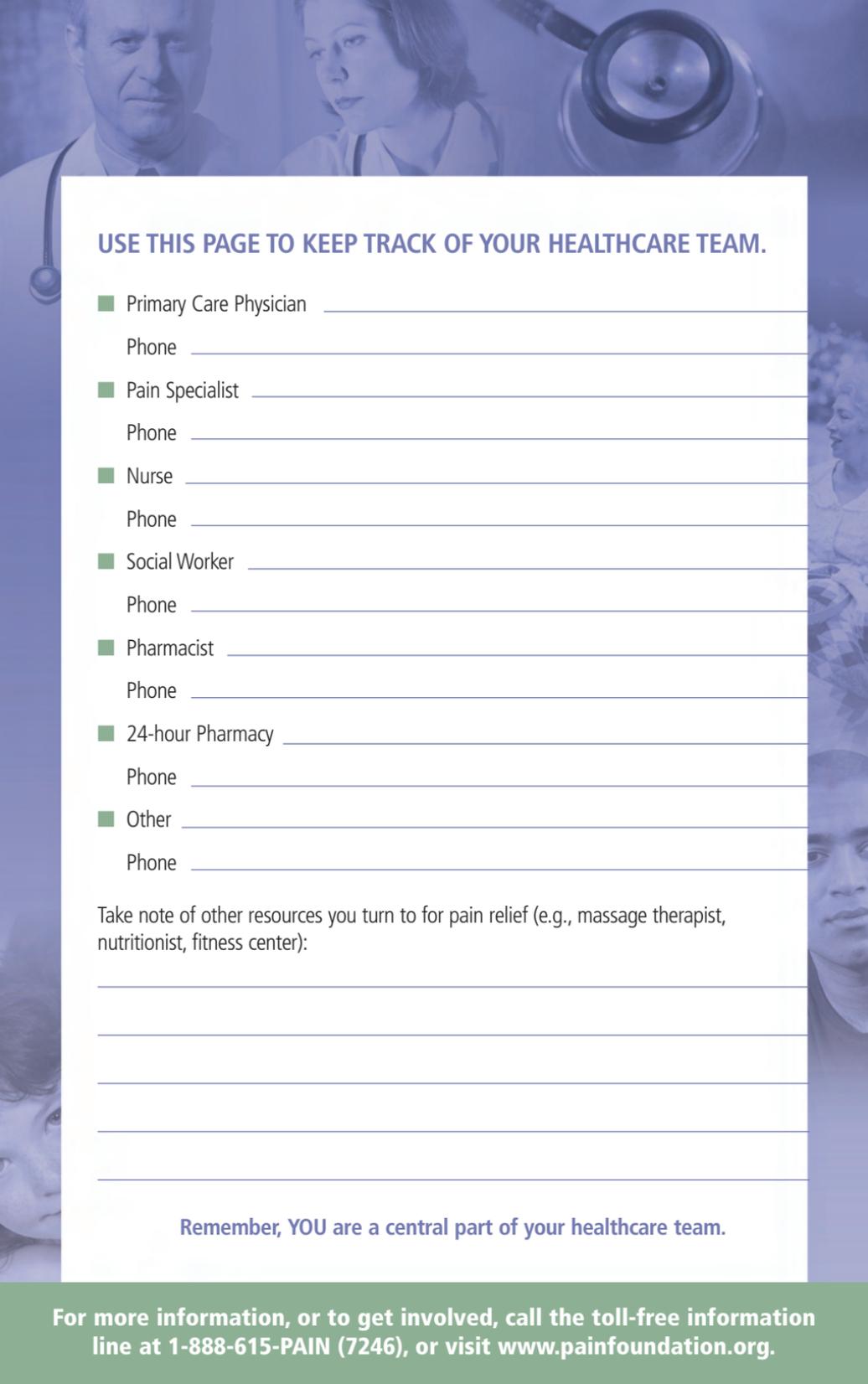
PAIN CARE BILL OF RIGHTS

AS A PERSON WITH PAIN, YOU HAVE A RIGHT TO:

- Have your report of pain taken seriously and be treated with dignity and respect by doctors, nurses, pharmacists, social workers, physician assistants and other healthcare professionals.
- Have your pain thoroughly assessed and promptly treated.
- Participate actively in decisions about how to manage your pain.
- Be informed and know your options; talk with your healthcare provider about your pain – possible cause(s), treatment options and the benefits, risks and cost of each choice.
- Have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- Be referred to a pain specialist if your pain persists.
- Get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.



Although not always required by law, these are the rights you should expect for your pain care.



USE THIS PAGE TO KEEP TRACK OF YOUR HEALTHCARE TEAM.

■ Primary Care Physician _____

Phone _____

■ Pain Specialist _____

Phone _____

■ Nurse _____

Phone _____

■ Social Worker _____

Phone _____

■ Pharmacist _____

Phone _____

■ 24-hour Pharmacy _____

Phone _____

■ Other _____

Phone _____

Take note of other resources you turn to for pain relief (e.g., massage therapist, nutritionist, fitness center):

Remember, YOU are a central part of your healthcare team.

www.painfoundation.org

1-888-615 PAIN (7246)

201 North Charles Street,
Suite 710
Baltimore, MD 21201-4111



American Pain Foundation

A United Voice of Hope and Power over Pain

September 2007