

A CONSUMER GUIDE TO OPTIONS FOR MANAGING CHRONIC PAIN

This is a stressful time for people who take strong medicines for their pain. The withdrawal of two COX-2 non-steroidal anti-inflammatory (NSAID) medications and the more stringent, FDA-mandated warnings on all NSAIDS have created fear and confusion about what's safe and effective for treating pain.

You may feel overwhelmed and confused. You may ask yourself, "What's safe? What medications can I take? What can I do now that I can no longer take this medication? What things can I do to improve my quality of life?"

The important thing to remember is that you are not alone. Millions of Americans suffer from chronic pain and there are many organizations working to address this serious, life-altering, and profoundly difficult problem. Now, more than ever, is the time to educate yourself about your treatment options and empower yourself by doing what you can to care for yourself physically, emotionally, and spiritually.

The American Chronic Pain Association, the American Pain Foundation, and the National Pain Foundation have prepared this guide cooperatively to help people with pain and their families better understand the current situation and to regain a sense of control over the critical and very personal decisions involved in managing chronic pain.

You can learn more about the resources offered by these organizations at our web sites:

- American Chronic Pain Association: <http://www.theacpa.org>
- American Pain Foundation: <http://www.painfoundation.org>
- National Pain Foundation: <http://www.nationalpainfoundation.org/>

Steps You Can Take to Feel More In Control of Your Pain

- Find a knowledgeable health care provider who understands pain and work with him or her to decide what's best for you. See the links below for help in finding a provider.
- Take care of the things you can control. Part of being an active participant is caring for your body. Get adequate rest, eat a healthy diet and engage in physical activity—all vitally important to maintaining function and health. Ask your physician which exercises are safe for you.
- In addition to a healthy diet and exercise, relaxation techniques such as meditation, visualization, hypnosis, and biofeedback may help you feel better. Your health care provider can help you decide which techniques may be beneficial for you.
- Pay attention to your emotional health. Taking care of the emotional aspects of chronic pain is necessary to treat your overall pain condition. Your physician may want to prescribe medication for depression, anxiety, and sleep disturbances and, in addition, may suggest

cognitive behavioral therapy (e.g., relaxation techniques, coping strategies, psychological therapy).

- Share your thoughts and feelings with loved ones and allow them to share their feelings with you. People cannot read your mind—just as pain is an invisible disease, emotions can be difficult to discern.
- Avoid isolation and loneliness by joining a support group. Rebuilding a life devastated by chronic pain is easier with the support and help of those who have been there and can help you find the way back. A good support group does not dwell on symptoms or losses, but rather focuses on positive actions you can take to improve the quality of your life—with a little help from your friends. See the Questions and Answers below to learn more.

Evaluate Your Treatment Options

Medications such as NSAIDs and selective NSAIDs (COX-2 inhibitors) are important tools in the management of chronic pain, but they are not the only tools available to help you. NSAIDs work by decreasing inflammation and pain. Traditional NSAIDs, such as ibuprofen and naproxen, tend to irritate the stomach and can lead to ulcers and bleeding. The COX-2 NSAIDs have become popular because they are less likely to cause ulcers and bleeding.

News that another NSAID has been withdrawn from the market and the fact that all NSAIDs will now have additional warnings on their labels can be frightening and disheartening. The first step in determining if NSAIDs and COX-2 NSAIDs are still an option for you is to speak with your doctor. You and your doctor are the only people who can determine whether a specific medication is the right choice for you.

If you are taking NSAIDs for pain, be sure your doctor knows your medical history, including any history of heart problems, high blood pressure, ulcers, and medication allergies. Be sure your doctor knows about all the medications you currently take, including medications prescribed by other doctors, over-the-counter medications, and supplements. This information will help you and your doctor weigh the overall risk-benefit of a medication.

It is up to you to educate yourself about your health and your treatment options. There are many options for your pain, including:

- prescription and over-the-counter NSAIDs;
- prescription medications such as opioids, anti-anxiety medications, anticonvulsants, antidepressants, muscle relaxants, and more, depending on your pain condition;
- complementary and alternative therapies, such as biofeedback, meditation, relaxation techniques, yoga, acupuncture, and more;
- physical therapy; and
- interventional treatments (eg, for arthritis, injections at the pain site containing a pain reliever and corticosteroid, or for back and neck pain, spinal cord stimulators and intrathecal drug pumps).

Talk with your doctor. Developing an open and trusting relationship with your pain specialist is important to helping you determine which treatment options are best for you.

QUESTIONS AND ANSWERS: RESOURCES YOU CAN USE

FINDING A HEALTH CARE PROVIDER

Is it important to see a pain specialist?

Many primary care physicians are well informed about treating pain and can be relied on to provide excellent care. But if you and your primary doctor agree, a pain specialist might be appropriate in your case. Pain specialists, like neurologists, cardiologists, and other specialists, have additional training and experience that you may find valuable.

To learn more, you may wish to visit these sites of organizations that serve pain specialists:

- [American Academy of Pain Medicine](#)
- [American Academy of Pain Management](#)
- [American Academy of Neurology](#)
- [American Board of Pain Medicine](#)
- [American Medical Association](#)
- [American Pain Society](#)
- [American Society of Interventional Pain Physicians](#)

What should I consider in selecting a doctor or pain program?

There are physicians who prescribe medications only for pain, physicians who do only functional restoration without medications, physicians who do only cognitive behavioral pain therapy, physicians who perform only blocks or do surgeries for pain, and physicians who might do combinations of these therapies. Some physicians, in an interdisciplinary fashion, provide expertise in all of the above interventions to patients in pain. You should know the type of pain clinic that you have chosen to visit. Choose wisely!

You may also want to consider a multidisciplinary pain management clinic or program. The American Chronic Pain Association has guidelines for selecting a pain management program at http://www.theacpa.org/pf_02_05.asp.

My doctor is not responsive to my questions and needs. How can I find another?

You have a right to be treated with respect and to have your concerns taken seriously. If your current provider does not measure up to your expectations, find another.

Many professional physician organization web sites have listings of their members available to the public. These directories can help you locate an appropriate pain medicine physician in your area. Print the directory and share it with your primary care physician to identify the best physician for your particular needs. You can call American Pain Foundation at 1-888-615-7246 (pain) for a list of pain specialists in your state or visit these sites for help:

- www.nationalpainfoundation.org/MyPain/TipsForFindingAPainPhysician.asp to see a list of online physician directories.
- www.painfoundation.org/page.asp?menu=1&item=4&file=page_resources.htm

- www.painfoundation.org/downloads/FindingCare.pdf

JUDGING THE BENEFITS AND RISKS OF MEDICATIONS

Where can I go to learn more about the medications I'm taking?

The American Chronic Pain Association offers a guide to medications currently used for pain treatment, including prescription and OTC drugs. It's also available in Spanish. To download it, visit: www.theacpa.org/pf_03_01.asp.

Medications for specific conditions are described on the National Pain Foundation site at www.nationalpainfoundation.org/MyTreatment/default.asp.

The American Pain Foundation offers a Pain Information Library at www.painfoundation.org/page.asp?menu=1&item=2&file=Library/Index.htm; click on Medications.

What are the risks posed by NSAIDs and Cox 2 inhibitors?

Research has indicated a greater risk of cardiovascular (heart) problems with these drugs, along with possible gastro-intestinal (stomach and intestine) side effects. While problems do not arise with everyone taking these medications, the FDA has determined that they should be used with care and that stronger warnings should be placed on their labels.

You can learn more about the issues related to COX-2 inhibitors and other NSAIDs at the Food and Drug Administration's web site at www.fda.gov.

What should I ask my doctor about the medications I'm taking?

Doctor visits can seem rushed and it's hard to remember all your questions when you are under stress. Good communication is at the heart of sound medical care and it's up to you as the consumer to set a tone for open discussion of your issues. Make a list of your questions before you leave for your appointment. If your doctor does not have the time to talk with you, ask to see someone else in the practice who can answer your questions. Many health care providers have patient education specialists, physician assistants, and well-informed nurses who are trained to help.

For more information about preparing for your doctor appointment and tools to create an inventory of your treatments, medications, and other health related issues, visit these pages:

- www.theacpa.org/hg_01.asp?id=73
- www.painfoundation.org/downloads/Notebook.pdf
- www.nationalpainfoundation.org/MyPain/inventory.asp

Will my doctor and/or pharmacist tell me about any side effects?

Most physicians and pharmacists will offer to discuss your medications with you. But to be sure that you know as much as you can about any medication you are taking, you should ask. Medical professionals respect your need to be an informed consumer. Don't be shy when it comes to your health.

In addition, all prescriptions have package inserts that describe the warning signs of possible side effects. Your pharmacist will review this with you if you ask. You also can visit the National Library of Medicine's site at www.nlm.nih.gov/medlineplus/druginformation.html.

Is dependency on a medication the same as addiction?

No. Dependency occurs when your body becomes accustomed to a medication and reacts negatively to its absence or a reduction in dosage. For example, a diabetic will react negatively to stopping insulin or an individual with depression to not taking an antidepressant, but these individuals are not considered addicted to their medications.

Addiction is a neurobiologic disease characterized by behaviors that include a lack of control over use of the drug, compulsive use, continued use despite harm, and craving.

What is tolerance?

Tolerance is a state of adaptation in which the use of a drug brings about changes in the body that result in a lessening of one or more of the drug's effects over time. That's why it's important to review your medications with your doctor on a regular basis.

For more information about dependency, addiction, and tolerance, visit these web sources:

- www.nationalpainfoundation.org/MyTreatment/Spotlight_Schneider.asp
- www.nationalpainfoundation.org/MyTreatment/MyTreatment_Addiction_and_Chronic_Pain.asp
- www.theacpa.org/pf_03_01.asp
- www.ampainsoc.org/advocacy/opioids2.htm
- www.painfoundation.org/page.asp?menu=1&item=2&file=QandA/Intro.htm and click on Addiction.

UNDERSTANDING YOUR CONDITION

How can I find out more about my condition and treatment options?

The National Pain Foundation web site has information about eight common pain conditions. You can find information about arthritis, back and neck pain, cancer pain, complex regional pain syndrome, fibromyalgia, headache, pelvic pain, and issues related to chronic pain and your mental health at www.nationalpainfoundation.org/MyPain.

In addition, the American Chronic Pain Association has links to many condition-related web sites. Link to the list at www.theacpa.org/pf_03_03.asp or go to www.theacpa.org, click on People With Pain and Their Families, then Resources, and find Health Conditions under the Links of Interest menu.

The American Pain Foundation also offers links to topic-related web sites at www.painfoundation.org/page.asp?menu=1&item=6&file=Links/Index.htm

Finally, you can find condition-specific information at many web sites, including:

- www.clevelandclinic.org/health
- www.nlm.nih.gov/medlineplus/healthtopics.html

HOW YOU CAN HELP YOURSELF MANAGE YOUR PAIN

Are there alternative therapies that can help me reduce my suffering?

As we have learned more about the connection between mind and body, the role of alternative therapies in treating chronic conditions has grown. Many people with pain find that therapies such as massage, yoga, tai chi, relaxation training, biofeedback, acupuncture, and more can help reduce the impact pain has on their lives. These therapies can be a helpful addition to, not a replacement for, traditional medical treatment. Discuss with your doctor what might be useful.

To learn more, visit:

- <http://nccam.nih.gov>
- www.nationalpainfoundation.org/MyTreatment/News_Complementary.asp and see Using Complementary Therapy to Relieve Pain
- www.painfoundation.org/page.asp?menu=1&item=2&file=Library/Index.htm and click on Complementary and Alternative Medicine

There also is information on alternative medications in the American Chronic Pain Association's Medication Supplement at www.theacpa.org/pf_03_01.asp.

Where can I learn pain management techniques that I can use on my own?

There are many ways to reduce your sense of suffering and improve the quality of your life in spite of pain. A key step is getting involved in your care and regaining control of your life by learning good pain management skills. Here are some good places to start:

- www.theacpa.org/pf_02.asp
- www.nationalpainfoundation.org/MySupport/default.asp

Are there support groups for people with chronic pain?

Rebuilding a life devastated by chronic pain is easier with the support and help of those who have been there and can help you find the way back. A good support group does not dwell on symptoms or losses, but rather focuses on positive actions you can take to improve the quality of your life—with a little help from your friends. The American Chronic Pain Association has groups across the country. Visit www.theacpa.org/aa_03.asp to find a group near you or visit the American Pain Foundation's PainAid at www.painaid.painfoundation.org or the National Pain Foundation's My Community at www.nationalpainfoundation.org/MyCommunity to join an online group.

What role can families and friends play?

When pain strikes one member of a family or social group, everyone suffers. As a caregiver, family member, or friend of someone with pain, you also have needs. The American Chronic Pain Association has a manual designed to address the needs of families who live with or care about people with pain. You can read more about it at www.theacpa.org/catalog.asp.

In addition, these links can help you keep a healthy balance in your life while appropriately supporting the person with pain.

- www.nfcacares.org
- www.wellspouse.org

UNDERSTANDING THE GOVERNMENT AGENCIES THAT REGULATE DRUGS

How can I find out more about the Food and Drug Administration?

Visit their web site at www.fda.gov.

How can I find out more about the Drug Enforcement Administration?

The Drug Enforcement Administration web site is <http://www.usdoj.gov/dea>

HAVING YOUR SAY

I want decision makers to know how I feel about this issue. How can I make my voice heard?

There are many ways you can play a role in shaping public policy on pain management. You can contact your elected federal and state officials and ask them to make pain care a priority. Find out how by visiting your state's Internet home page or these national links:

- www.senate.gov
- www.house.gov

You can ask your member of the House of Representatives to support HR 1020, the National Pain Care Policy Act of 2005. For more information about the bill and what you can do to support it, visit the American Pain Foundation's online advocacy center www.painfoundation.org and click on the TAKE ACTION! button.

For a guide to having September declared Pain Awareness Month in your state or community, download the Partners for Understanding Pain Proclamation Tool Kit at www.theacpa.org/documents/Proclamations%20Process%20Guide%20Tool%20Kit6.pdf.

To help you create awareness in your communities about the far reaching implications pain has on an individual's life, go to www.nationalpainfoundation.org/NationalPainAwareness/default.asp.

Finally, there is a Pain Advocacy Tool Kit available for those who want to play a more active role at www.partnersagainstpain.com/painadvocacycommunity.