Trying to treat something that is invisible brings forth challenges, obstacles, and belief systems that may prevent proper treatment. Chronic pain clearly falls into this category. Science is based on facts. If something cannot be measured, weighed, or viewed in any way, then skepticism may often arise. Pain is invisible and can be caused by a vast array of health problems. But when pain makes its presence known, our first response is to seek help. Typically that is an easy process. It is only after numerous attempts, many unsuccessful treatments, and painful procedures that the pain can gain control of our life. We are often at a loss to understand what our next steps should be in our attempts to find relief.

To complicate matters, we have grown up hearing that we should avoid and even fear certain methods of pain relief, like medication. Many of us have heard the myth that opioids are addictive and should be avoided. True, they are not for everyone. But for some they are one of the many tools needed to manage pain so that people can improve the quality of their lives and reduce their sense of suffering.

I think that Russell Portenoy, M.D., of Beth Israel Medical Center put it best. “Many people think that addiction is common because they mistakenly believe that a person who goes through withdrawal if their drug is stopped is addicted. In fact, a person who experiences withdrawal is physically dependent; physical dependence is a normal response to chronic opioid therapy and is not important to the patient as long as the drug is not stopped suddenly.”

September 12, 2006 is the Global Day Against Pain in Older Adults (see UPDATE on page 10)
Ginny Kelly’s daughter made the mistake of giving her mother a book which claimed that back pain was caused by emotions.

“I read the first chapter and called her. I was really angry,” said the 61-year-old California resident. “I told her ‘I KNOW what caused my pain.’” Ginny believes that one of the most harmful chronic pain myths is: “you cause your pain by your unhappiness.”

Myths about chronic pain abound, hurting the person with pain, their relationships with others, and the medical treatment they get, or don’t get.

ACPA support group facilitator Steve Sibley of Santa Cruz, California, won’t even go to an emergency room any more. “They do the best they can to keep pain patients from getting medication,” he said. Eva Everhart, 48, of San Diego, California, agreed: “I never want to go back to the ER again. I was treated so badly, like an addict,” she said.

It’s All in Your Head

Persons who have chronic pain commonly find they are treated as if they want drugs, attention, or an excuse to get off work. These ACPA facilitators were often made to feel as if their pain were either self-caused or “all in their head.”

“Pain is an invisible problem that other people can’t see,” said Steve. “If they don’t see it, they don’t believe it.”

Steve should know. For eight years in the 1990s he was told his back pain was his own creation. But when tests finally showed that he had Ankylosing Spondylitis (a painful misalignment of the vertebrae), “the medical professionals apologized to me,” he said.

Steve was also denied narcotics by doctors who believed the myths of easy addiction to those drugs. His own belief in the addiction myth caused him—when he finally was given strong pain medication—to try stopping the narcotics several times, only to end up in the hospital because of the severity of his pain.

Through research, reading, and request- ed tests, he discovered that some of his problems could be helped by diet, supplements, reduced medications, and physical therapy. He felt better. When his pain escalates, he is able to bring it down to manageable levels by similar methods, he said.

Imaginary Pain

Not being believed when you describe your pain can contribute to depression, said Anna Fox, 55, of Sui Sun, California. She wondered at times if

"Now I live with the same level or more. What has made the difference? It’s attitude. Distraction, relaxation, and positive thinking are part of my pain management arsenal."

Anna worked with a psychologist who taught her how to turn off the brain signals that send the pain. “It’s sort of like self-hypnosis,” she said. “I was hard-headed about it, very skeptical.”

Anna practiced until the method became automatic and is now 99 percent pain free.

The Doctors Will Fix It

Ginny Kelly, who manages chronic nerve pain in the thoracic area of her back, said she once believed many myths about chronic pain. She thought that when doctors found the cause (myth number one), they’d be able to fix it (myth number two). Now she hears many new members of her ACPA group holding onto a similar myth: “In time I’ll be back 100 percent.”

Ginny said she also believed that, “if it can’t be fixed, there’s a medication that can control it; then I’ll be able to be healed and go back to work.” Her back spasms had torn ligaments and created problems with the facet joints of her vertebrae. She couldn’t tolerate strong pain medications, trigger point injections did not help, and massage, acupuncture, and chiropractic treatments just “made it worse,” she said.

"Now,” she said, “I live with the same level or more.” What has made the difference? “It’s attitude,” she declares.

Steve Sibley works with people who are disabled, and helps his clients get a new perspective on their situation. “The whole thing is being active, seeing a purpose,” he said. Realizing he was not alone in his struggles also helped.

“Pain is hard to put in its place because it’s such a powerful thing, but it’s really just a small percentage of what a person is,” he said.

Family Misunderstandings

Myths about chronic pain strongly affect family and friends too. Steve said that constant pain “tore my family apart,” resulting in two divorces and estranged feelings with his parents and siblings.

When Eva began her odyssey with chronic pain, she expected family and friends to be supportive and stand by her. She said, “I don’t think people understand when something’s chronic. You can’t just find another doctor. They say, ‘I’ve had pain before and it didn’t stop me.’”

The Myth of Addiction

Eva, who wished to be anonymous, found the myths that doctors perpetuate about addiction and alternative medicine to be hindrances in her pain treatment. She had severe spasms in her neck, a cervical dystonia called Spasmodic Torticollis. Valium was one of the few medications that helped, but at the time her doctor refused to prescribe it. Later in her pain journey, she found that homeopathy helped. She explained, “It’s not that you want to tell the doctors what to do, but you want them to listen to you and work with you.” She has a new doctor now and only takes medications occasionally.

Through ACPA Eva learned the value of pacing, meditating, and stretching to help with the constant pain. “I’m learning not to say ‘Oh, I’m having pain, I better lie down,’ but ‘Oh, I’m having pain, I better do the stretching.’” By using tapes, meditation, and relax- ing play with her two dogs, Eva has been able to return to part-time work.

Distraction, relaxation, and positive thinking are part of her pain manage- ment arsenal. On bad pain days, she reminds herself that there will be better days ahead.

It also helps to talk to members of her ACPA support group, because, “you can say what bothers you and know that nobody in the group is going to judge you or say you shouldn’t feel that way.”

Anna’s friends didn’t always under- stand when she would cancel an engagement at the last minute because of a flare-up or unpredictable chronic pain. “I need to have the freedom to call it off and not ruin the relation- ship,” said Anna. Over time friends come to understand, she said, “but now they hesitate to invite me.”

Loved ones who stick around can be the most wonderful support. Ginny credits her husband of 40 years with keeping her going. “With him the glass isn’t half full, it’s overflowing,” she said. “He comments that everything changes and it doesn’t always change for the worse.”

Battling myths turned some facilitators into activists. As Steve said, “My doctor tells me that I’m not just doing it for myself, I’m doing it for others in the same situation.”

Anna is also more assertive and takes an active role in her health care, which has improved her care and her rela- tionship with her doctor. A positive attitude helps her manage depression. “Overcoming these myths has taught me to be organized and confident,” said Anna.

Many people with pain list questions for their doctors. Steve also keeps a running list of his meds, including dosages and when taken. Eleven years of this detailed documentation has “given me the perspective that some times things were better than I thought. Seeing that there’s a cycle there, I can look forward to times when I have less pain,” he said. “I can have some kind of control over the pain.”

Familiar Myths Distort the Perceptions of Pain

by Sally Price

* Not her real name
People with chronic pain often face the difficult choice of whether or not to take what many call “pain pills,” or opioid medication. On the one hand, your doctor may recommend this medication as an important means of providing needed pain relief. On the other hand, you may hear that such medication is “addicting,” and you don’t want to add an addiction problem to an already-existing pain problem. Furthermore, you don’t want to take a medication that sedates you so much that you can’t drive, think clearly, and maintain good coordination.

The word “opioid” has largely replaced “narcotic,” which suggested recreational or illegal drug abuse. Opioid medication does have a chemical structure like opium and blocks pain by acting on sites in the brain that record pain from multiple areas of the body. Opioids commonly taken for chronic pain are morphine, (MS Contin); hydrocodone (Lortab, Lorcet, Vicodin); oxycodone (OxyContin); hydromorphone (Dilaudid); methadone of entanyl (Duragesic patch). There are many other examples.

In the early days of chronic pain management (1960s through 1980s), pain experts typically regarded use of opioids as an example of “pain behavior” that interfered with long-term functioning and needed to be discontinued. However, subsequent research from cancer centers, particularly by Kathleen Foley and Russell Portenoy at Memorial Sloan Kettering in New York, suggested that many patients with cancer pain could take such medication with significant pain relief and relatively little interference with function. Their suggestion that the same findings might hold for other types of chronic pain besides cancer led to a great deal of research and increased use of opioid medication for chronic pain.

Major Societies Review Opioids

Summarizing findings to date, the American Pain Society and the American Academy of Pain Medicine published a position paper in 1997 on the use of opioids for chronic pain management (available at: www.painmed.org/product-pub/statements/pdfs/opioids.pdf). This paper concluded that side effects of opioid medication can usually be managed well or dissipate with time. Tolerance, which is defined as decreasing effectiveness as a drug continues to be taken, “… has not proven to be a prevalent limitation to long-term opioid use,” and dose levels often can be increased without significant harmful effects.

Studies … have revealed very limited dysfunction in cognitive functions as a result of opioid use.

The paper also called attention to confusion related to the word “addiction,” and defined it as “a compulsive disorder in which an individual becomes preoccupied with obtaining and using a substance, the continued use of which results in a decreased quality of life.” This definition clearly differentiated “addiction” from tolerance and physical dependence, the latter referring to negative symptoms occurring for a short period of time following abrupt withdrawal of a substance. (Indeed, this dependence can occur with prolonged use of opioids and suggests the need to withdraw gradually and with physician guidance and supervision.) Using this definition, people with chronic pain clearly are very different from recreational opioid users and substance abusers and are rarely addicted.

Studies Examine Effects

The results of hundreds of studies on opioid medication for chronic pain are difficult to summarize in a few sentences. Opioids clearly are not “cures” for pain and about a 40 percent mean relief of pain is often reported, with a lot of individual differences. Opioid medication often is best used in combination with other treatments. Some types of pain, such as pain from muscles and joints rather than nerve pain, seem to respond better to opioids. There are also some people, such as those with major breathing problems, who should stay away from opioids. Some do have some problems with feeling sedated and/or constipated.

Many studies investigate how opioids affect cognition, which refers to an individual’s ability to use his or her brain to perform mental activities, and psychomotor tasks, which involve use of the brain for movement.

Starting an opioid or increasing the dose has been found to create sedation and to risk impairment of such functions for several days in many individuals. However this impairment and sedation typically reduce within a week.

Given the fact that opioid medications now are prescribed to relieve pain for indefinite periods of time, a more critical question relates to effects over months and years. To answer this, researchers have used a variety of techniques to test the effects of opioid use on many cognitive and psychomotor skills, including short-term and remote memory, ability to learn new tasks, comprehension and arithmetic, eye-hand coordination, reaction time, balance, and driving skills.

Research studies have:

- Compared performance of chronic pain patients with and without such medication, often using a control group of those with no pain and using no such medication.
- Tested the same individuals with chronic pain before and after they started on opioid medications.
- Examined epidemiological data, reflecting statistics in large population groups, such as the vehicle accident rates in individuals with and without opioid prescriptions (which, incidentally, have not generally been found to differ much).

Obviously, when a large number of studies are performed using different methods and populations, results can differ from study to study. However, the wide majority of studies addressing longer-term effects of opioid use (ranging from one week to many years) have revealed very limited or no dysfunction in cognitive functions as a result of opioid use.

Several have found that pain interferes with many cognitive functions and that taking opioid medication may then actually improve cognition by relieving pain.

People with chronic pain clearly are very different from recreational opioid users … and are rarely addicted.

Driving Ability and Opioids

Given the fact that driving is such a vital part of modern life, our group at Emory University tested how opioid use affects driving ability by measuring:

- Driving errors on the road,
- Performance on a difficult driving obstacle course, and
- Reaction time and inattention during a monotonous computer test.

We found almost no differences among people with chronic pain taking or not taking opioids, and individuals without pain. Despite these findings and similar ones from other studies, individuals should be aware that in many states, they risk being charged with driving under the influence if they are stopped by the police and found to have opioids in their systems.

In Conclusion

These data might bring a sigh of relief to people worried about not being able to think or function with long-term use of opioids. However, a few points need to be remembered.

- There are a lot of individual differences in responses, so one’s own experience might be different from that of most people.
- There are many different types of opioids and dose levels, and not all have been fully tested for their effects.
- The effects of combinations and interactions of drugs have not been well tested.

Drug interactions clearly need to be studied, given the large number of people with chronic pain who take opioids in combination with other drugs that affect the central nervous system and may be sedating, such as antidepressants, tranquilizers, and muscle relaxants. It is vitally important for everyone to be cautious in performing tasks that involve safety risks while on opioid medication for pain and to work closely with their physicians regarding decisions about all medications used to treat pain.

Stanley L. Chapman, Ph.D. is a psychologist in the Department of Anesthesiology, at the Emory University School of Medicine.

Selected References


Understanding Cauda Equina Syndrome

Cauda Equina Syndrome (CES) is a little-known form of spinal cord injury that can cause severe, ongoing chronic pain. Though it is often caused by a slipped disc, it is not related to the usual type of “back trouble” that many people experience. Improving awareness of CES can encourage people to recognize this condition and seek prompt treatment.

On the forefront of this effort is the Cauda Equina Syndrome Support Group (CESSG), an international, web-based support group of more than 700 members, helping people who have complications of CES. CESSG operates a Resource Center at www.caudaequina.org. Here, they share information, personal experiences, and triumphs.

The cauda equina is the lower part of the spinal cord. CES is a neurological (nerve) condition, with a number of causes that can occur as an emergency or a chronic condition. When damaged, these nerves exhibit a specific pattern of symptoms:

- Severe pain in a radicular (nerve root) pattern in the back, buttocks, perineum (saddle area), genitalia, thighs, and legs
- Loss of sensation, often with tingling or numbness in the saddle area
- Weakness in legs, often asymmetric
- Bladder, bowel, or sexual dysfunction and incontinence
- Loss of reflexes in the knee, ankle, anal and bulbocavernosus (a muscle of the perineum)

An inability to pass urine is a major warning sign. Some physicians consider this combination of symptoms to be a medical emergency, requiring immediate attention to avoid permanent nerve damage. Anyone who has these symptoms should immediately contact his or her doctor, who will most likely order an MRI or a myelogram with CT scan. The longer the nerves are crushed the more likely one is to have permanent nerve damage.

The cauda equina can also be damaged by prolapsed disc, spinal fracture, chronic compression, slipped vertebrae, inflammation, or loss of the myelin sheath, as in multiple sclerosis.

CES due to compression or distortion may respond well to medical treatment. CES can also be chronic and progressive, a devastating condition that can have a drastically negative impact on one’s personal image, self-esteem, social life, work, and relationships. Sufferers are faced with:

- Severe pain
- Loss of muscle power
- Frequent urinary infections
- Socially unacceptable continence problems
- Neurogenic pain tends to be worse at night, interfering with sleep. People with CES also feel pain in numb areas, which can be of a burning nature. Weakness may occur in the legs and make walking difficult. Severe nerve-type pain may be resistant to treatment and require strong painkillers. Side-effects may cause further problems, such as electric shock-type pain or pain from non-painful stimuli such as light touch.

CES sufferers may become depressed, which is not surprising when they are constantly challenged to maintain a bowel and bladder program, walk without pain, and deal with loss of sexual function due to lack of nerve sensation. As a result, some lose their jobs, social standing, and family relationships.

Low dose antidepressants and anti-seizure medications like Neurontin, Zonegran, and Topamax are usually more often helpful for nerve pain than narcotics. While some side effects should subside, careful monitoring by a physician is needed to balance medications to achieve good pain relief with a minimum of adverse effects.

Physicians may also be able to treat some bladder dysfunction, through suffers will also need to make changes in diet and adjust behavior when faced with loss of bowel control. Support groups can help counter the sense of isolation and depression, help fellow sufferers hold on to their hope, and guide them toward treatment.

The information in this article is drawn from the CESSG web site. For more information to go to www.caudaequina.org or write to Vickie Wolfe, president, at 14 wolfe@comcast.net or Sandi Kleps, vice president, at https://gail.net.

Myths CONTINUED FROM PAGE 1...

Addiction is a disease, which is defined by craving, loss of control over the drug, compulsive use of the drug, and continued use of the drug despite harm to the user or others,” he said.

Like all other medical treatments, medication is something you need to discuss with your health care provider. This will help you to see which, if any, medication may help you to best manage your pain. In this issue of The Chronicle we will explore other myths about chronic pain like:

National Depression Day Helps Identify Problems

Mental health screenings have helped individuals with pain, and others, identify emotional problems, such as depression and anxiety.

Screening for Mental Health, Inc. (SMH) first introduced the concept of large-scale mental health screenings with National Depression Screening Day (NDSD) in 1991. It has been expanded to include both in-person and online screening programs for depression, bipolar disorder, generalized anxiety disorder, post-traumatic stress disorder, eating disorders, and alcohol problems, and for suicide prevention.

In 2005, clinicians conducted nearly 600,000 screenings at mental health facilities, hospitals, primary care offices, social service agencies, colleges, workplaces, schools, and the military. In all, 12,000 facilities have used SMH programs. This year’s event is scheduled for October 5, 2006, helping to educate individuals about the warning signs of mental disorders and show them how to gain access to treatment.

Additional information on conducting or receiving a screening can be found on the NDSD web site at www.mentalhealth-screening.org. NDSD also offers education information, a new video, suicide prevention materials, and updated clinician education resources.

“Enduring pain builds strength and character,” or “If my pain increases I must be getting worse.” You can read what other American Chronic Pain Association members have to say about pain management and the myths they have encountered in their journeys.

For more information on medications used for chronic pain, refer to the American Chronic Pain Association Medication Supplement which is available online at www.theacpa.org. It is written each year by Steven Feinberg, M.D., member of the ACPA Board of Directors and associate clinical professor at Stanford University.
Counterirritants are topical analgesics that stimulate the nerve endings in the skin, causing a feeling of cold, warmth, or pressure. To alleviate pain, a doctor will often recommend a topical pain agent. “Topical” means that the patient applies this medication directly to the skin in the form of a cream, spray, patch, or rub. Topical agents are available both over the counter and by prescription.

Topical pain treatments are another tool that people with chronic pain can use as part of a comprehensive strategy for managing their pain. Topicals may be used alone or to supplement other medications, as an effective delivery system for specific conditions. They are often used as an initial step because they are not addictive and have few side effects. People are looking for topical analgesics that fit their lifestyle.

Topical Analgesics Decrease Sensation
Topical pain relievers are classified as either analgesics or anesthetics. An analgesic is a drug that works to increase the body’s tolerance for pain and decrease the sensation of pain. Salicylates, which come from the bark of a willow tree, contain the pain-relieving ingredient salicylic acid, which is a chemical similar to aspirin. Salicylates are used to treat inflammatory conditions such as arthritis, and arthritis creams such as Icy Hot, Arthricare, and Mineral Ice are specifically approved for minor pain such as backache or a sprain.

Topical anesthetics like EMLA can also be effective in the treatment of nerve damage from decreased blood supply and conditions where the nerves are not functioning normally. Studies show that EMLA can reduce the acute and chronic pain following breast cancer surgery.

Counterirritants are topical analgesics that stimulate the nerve endings in the skin, causing a feeling of cold, warmth, or itching. This tingling can neutralize the severe pain of an injury. Well-known counterirritant creams such as Icy Hot, Arthricare, and Mineral Ice are specifically approved for minor pains such as backache or a sprain.

Considerations
Topical pain relievers are not for every patient or every situation. “Topically acting drugs work only on the skin and do not affect deeper tissues,” said Dr. Loeser. “Topical medications are most useful for localized pain syndromes and less useful for widely distributed pain problems.”

Transdermal Opioids Work Differently
Though Fentanyl and other opioid transdermal patches are also applied to the skin, these patches work differently in the body. “Although the medicine is applied topically, it works systematically and has all of the side effects and potential hazards of oral opiate,” explained Dr. Loeser. Transdermal opioids can be habit-forming and should be used only under a doctor’s supervision.

Side effects of topical anesthetics are usually minimal, but might include redness or slight swelling at the site of application. These conditions usually disappear within a few hours of removing the medication.

People are looking for topical analgesics that fit their lifestyle.
ACPA Update

New ACPA Groups
Welcome to our new groups and facilitators.

Barbara Lyn Donohue
Arlington, VA

Gerald Evans
Santa Ana, CA

Jeane Taylor
Santa Rosa, CA

Margaret Reilly-Sabourin
Santa Rosa, CA

Steve McDaniel
Elliottville, IL

Marie Pappas
Milford, MA

Sal Serra
Goodrich, MI

Leone Barnes
Mt. Morris, MI

Terri Hinton
Raleigh, NC

Fred Seeley
Albuquerque, NM

Global Day Against Pain
The aim of the International Association for the Study of Pain’s (IASP) Global Day Against Pain is to raise awareness of a different aspect of pain each year. This year’s theme is “Pain in Older Adults.” After the kick off on Global Day Against Pain, September 12, 2006, this theme will be emphasized throughout the year with updated materials being posted on www.iasp-pain.org/GlobalDay-2006.htm.

IASP chapters and individuals involved in research and treatment are organizing IASP Global Day Against Pain events in their communities to focus attention on this facet of pain, with the ultimate objective of improving pain relief in older people throughout the world. There will be a Press Conference on September 12. Watch for details on the Web site.

ACPA Accepted for Federal Campaign
The ACPA has been accepted as an approved charitable organization for the Fall 2006 Combined Federal Campaign (CFC) with agency code #3399. The CFC is the world’s largest annual workplace giving campaign. Pledges made by federal civilian, postal, and military donors raise millions of dollars each year to support non-profit organizations that provide health and human service benefits.

If you work for a CFC organization, please consider making a donation to the ACPA. And if others you know participate in a CFC program, please let them know that they can contribute to the American Chronic Pain Association.

Pain Treatment Improves in N.Y.
In June 2006, the New York State Legislature passed the Palliative Care Education and Training Act to improve palliative care and pain management. Initiated by Compass & Choices, the legislation is the first of its kind in the nation to address the crisis of under-treatment of pain. It will:
• Establish a statewide advisory council on palliative care and pain management;
• Create undergraduate and graduate palliative care training programs using up to $45 million;
• Establish state centers for palliative care excellence;
• Establish a pharmacy advisory council;
• Support the development of new pain management strategies;
• Establish a registry of pain specialists.

This is part of a series of articles intended to give readers more insight into the interests and contributions of ACPA board members.

Steven D. Feinberg, M.D., Physiatrist and Pain Medicine Specialist, is the Medical Advisor to the ACPA, as well as an active board member.

At his Palo Alto, California practice, he evaluates complex cases of nerve and chronic pain syndromes, complex regional pain syndrome, trauma disorders, and spinal, orthopedic, burn, and repetitive strain injuries, among other illnesses.

Dr. Feinberg is a Stanford University School of Medicine Adjunct Clinical Associate Professor. He received the 1998 Professional of the Year Award from the California Governor’s Committee on Employment of the Disabled and is the recipient of the 1999 American Academy of Pain Medicine Founders Award. He is also a monthly contributor to the California Workers’ Compensation Educator (CWCE) magazine.

ACPA board member Ed Covington first asked Dr. Feinberg to serve, about 12 years ago. “He said it wouldn’t take much time,” Dr. Feinberg recalled. Now he writes articles for The Chronicle, updates the annual Medication Supplement, makes referrals, answers questions, and “anything else they need,” he said.

While in medical school, Dr. Feinberg considered going into family practice or psychiatry. During his residency at the University of Washington, he met Dr. Wilbert Fordyce, an early authority in the psychology of pain control. Dr. Fordyce suggested that specializing in pain medicine would let Dr. Feinberg explore the psychiatric aspects of pain management as well as build relationships with his patients.

Dr. Feinberg is a past president (1996) of the American Academy of Pain Medicine and a former president and longtime member of the Board of Directors of the California Society of Industrial Medicine and Surgery. As Program Consultant to the Bay Area Pain & Wellness Center Functional Restoration Program in San Jose, he helps many injured workers reestablish more normal everyday life activities and return to work.

“My patients fill every minute in my life,” he said. Dr. Feinberg also knows pain personally. Following two failed neck surgeries, he has chronic pain in his head, neck, and right arm.

Dr. Feinberg hopes that the ACPA will increase efforts in recruiting patients as members and would like to see it have 10 times the current size. “ACPA’s work is morally and ethically important. The political and educational all blend together,” he said.

“We should also expand our Internet-based learning tools with more medical topics discussed at a layman’s level,” he said. “Most people need to self-manage their pain. The locus of control must switch to the individual.”
Starting a chronic pain support group can be the most rewarding thing you've ever done. It can also be the most difficult. I began a chronic pain support group in 1993 after I had been diagnosed with rheumatoid arthritis. My friends and most family members did not—and could not—understand what I endured living every day with chronic pain. I found myself growing bitter.

Then one day, as I stepped onto the sidewalk, a homeless man passed by. He saw me wince as my inflamed knee buckled under my weight. Looking into my eyes, he said gently, “Your knee hurts. I hope it gets better soon.” Then he walked on.

Those simple words changed my life. This stranger, this man who had his own pain and his own troubles, reached out to me. At that moment, I realized I had to find other people who also understood. Nine months later, I joined four people to talk about chronic pain and how it had changed our lives. This August our support group will celebrate our 13th anniversary.

That first meeting, I found myself nodding again and again, “Yes, that’s just what I feel.” At almost every meeting, we have a new member shyly peek in the door and join us. I see that look on their faces, too, first of amazement and then of relief, that, here, finally, someone understands.

Here are some guidelines I followed when setting up the Chronic Pain Support Group.

Resources
- Attend a support group in your local area to see how it operates. You can learn from them even if they don’t address a problem you share. Consult with the group leaders and ask them for advice.
- Read all the information you can find on support groups: what they are, what they do, various ways to run them, pitfalls, and benefits.
- Make use of materials developed for support groups such as those from the Arthritis Foundation, which co-sponsors our group, and from the American Chronic Pain Association. Our group’s Web site (www.desktoppub.com/support) has information and hints on starting your own support group.

Publicity: Getting the Word Out
People often hear about our group from other members, which is especially important at the beginning to build up membership. We’ve also grown through:
- Referrals from doctors and other health-care providers who have been speakers at our group
- Members who tell their own doctors and other health-care providers about us
- Press releases about upcoming meetings reported by local newspapers, radio stations, and cable TV stations
- Newspaper articles about special events, and members’ personal stories. (If you invite a reporter to the meeting, be sure to get permission from the group members first.)
- Brochures and meeting flyers displayed in doctors’ offices, pharmacies, local libraries, and other venues.

Because I have a desktop publishing business, I am able to put out an occasional two-page newsletter sent to members, friends, and professionals anyone who has ever attended a meeting. It includes information of interest to members as well as a schedule of meeting dates and topics. Our local hospital pays for the copying and postage charges; you may be able to make similar arrangements.

I send out an email meeting notice reminder to all members. We also have a Web site (www.desktoppub.com/support) with information about the group, contact info, links, and resources.

Signup Table
We have a signup sheet at meetings which lets us collect and share names, addresses, phone numbers, and e-mail addresses, essential to staying in touch and sending support. At the signup table, we have a basket for donations for the meeting place year-end gift and group expenses (postage, etc.). There are also pamphlets, books, tapes, videos, magazines, and other materials for people to take home.

Meeting Structure
Once people have signed in, we gather in a circle, introduce ourselves, and I give a short meditation or relaxation reading. At least one meeting a month, we have a general discussion group, developing some topics ahead of time.

When we have a speaker, I still include a break with refreshments, as it is a good time to get to know people better and to draw out some members who are shy.
In Memory of
Rev. Lawrence Bennett

Given by
Susan, Richard and Ashley Webb
Andrea McLendon
Suzann S. Barthold
Susan H. and David A. Hicks
Lester and Marguerite Hilbert

Mary “Kay” Farrell, 64, of San Diego, Calif., died June 16, 2006. Born on Dec. 10, 1941, she had four children and seven grandchildren.

Kay Farrell was the leader of the San Diego chapter of the ACPA Chronic Pain Support Group for more than 10 years. She dedicated herself to assisting others who were experiencing chronic pain. Even as her health declined, she faithfully made certain the group continued their twice-monthly meetings.

She was generous with her time and limited money. She invited members to call her day or night because, as she often said, “I know how it is to be unable to sleep, due to the pain.” If donations were scarce, she never hesitated to pay for long-distance calls, postage, and refreshments out of her own pocket.

She combed newspapers and magazines, clipping relevant articles to bring to the meetings. In gratitude, the members threw her a party on her tenth anniversary as group facilitator. Everyone chipped in for a cake and special gift.

The first year I was in the group, I called Kay for advice on how I could possibly host Thanksgiving dinner. Ever the practical realist, she suggested paper plates, frozen pies, and other ideas to make things simple for me. She said that my friends and family knew of my condition and would not complain. She was right! The holiday meal went off without a hitch and I didn’t suffer any increase in pain.

Kay will be greatly missed. She staunchly supported all with chronic pain.

In Memory of
Kay Farrell

by Nancy Street

We welcome gifts in any amount:
- Supporting Contributor: Up to $25
- Sustaining Contributor: $25 to $50
- Patron: $50 to $100
- Hero: $100 to $250
- Champion: $250 to $500
- Angel: Over $500

The ACPA is a peer support organization. We help each other learn to live fully in spite of chronic pain. We also need to join together to make sure the ACPA continues to be there for us all with resources, materials, and that personal contact that can make such a difference.

Your membership, donations, and purchase of materials help the ACPA alive and reaching out to even more people with pain. Thank you for helping us help others.

To Join The ACPA:
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Today's Date
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$30.00 First-Time Membership: You’ll receive the ACPA Member Workbook Manual, Patient to Person: First Steps, a one-year subscription to the ACPA Chronicle, a 10% discount on all other ACPA materials, and a membership card.

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To Donate to The ACPA:
I want to help the ACPA. Enclosed is my tax-deductible donation of $.
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We accept payments by check, credit card, and PayPal. Please return the completed form to: The ACPA, P.O. Box 850, Rocklin, CA 95677
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