



CHRONICLE



The Maze of Pain

by Penney Cowan, Executive Director, ACPA

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As we search for relief, people with pain can feel as if they are trapped in a never-ending maze.

Like most of us, you probably began with your primary care physician, believing your doctor would know what was causing the pain and how to treat it. Then life would go back to “normal.”

The first few attempts at diagnosing and treating the pain may not have been effective, but you were still hopeful that there was an end in sight. It wasn't until first you heard, “You will have to learn to live with it,” that you began to lose hope. You found yourself going from one doctor to another, one test to another, or one treatment to another, all coming back to where you started—pain. Perhaps, it was at this point that you first felt as if you were trapped inside a maze with no exit in sight.

It is our hope of finding some type of relief that keeps us in the maze, wandering around in search of the smallest bit of relief. Because our desire for relief is paramount, we expend more effort than we ever thought we would. We continue to travel the maze of pain, still hoping, but our hearts feel more hopeless with each new dead end we encounter.

Necessary Detours

What we fail to realize is that living with pain is not a simple, straight line. It is filled with many twists and turns. And around each corner, with each new journey, we can learn something



new, feel the slightest improvement, and increase our level of functioning by a fraction. Our journey is long, exhausting, and often expensive in more ways than one. But this is the journey that we must travel when pain becomes part of our daily life.

Our theme for this issue is unusual approaches to pain management. Whether your approach is typical or atypical, the key element in your journey is YOU.

In most health care issues, you are a patient turning to the medical community to relieve your pain and suffering. But when it comes to dealing with chronic pain, the rules change. The person with pain must take an active role in the treatment. And, traveling through the maze of pain is necessary if you are to reduce your sense of suffering and improve the quality of your life.

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Managing Pain: Finding What Works for You

On the journey from patient to person, people with chronic pain must find the combination of treatments and activities that work for them personally. These successes involve tools and techniques that may or may not work for anyone else. We share four such stories here.



Nancy Gordon's healing dogs include Toaster, around her neck.

movies and ask her boyfriend to put her heating pad in the movie theater popcorn machine to warm it up. "Toaster resolved that problem," she said with a laugh.

Toaster does more than warm necks and other body parts. She retrieves items, operating on commands she learned during two years of training to become a certified service dog. Offering service dogs for people with chronic pain is a growing specialty.

Discovered by Television

In 2002, when Toaster was three years old and about to have puppies, she appeared on the cable television channel Animal Planet.

After the TV program was aired, Nancy was "deluged with people asking if I could help them find a Toaster of their own," she said. She is still receiving emails, totaling more than 600 now. "The writers were inspired by the story that gave them hope that there could be something else that could help them besides pain medication," she said.

Dogs Provide Help and Heat

by Sally Price

How Nancy Gordon of San Diego, California, went from an auto accident in 1992 to a dog wrapped around her neck as a heating pad in 1999 to an inspirational greeting card/gift line in 2005, is a fascinating story.

At the time of the accident Nancy lived in Oregon, working as a licensed clinical social worker. After the accident, she thought she had a severe whiplash. But three years later she learned her pain was from fibromyalgia and chronic fatigue immune deficiency (FMS/CFIDS). After six years of trying to balance work with severe pain and fatigue, she gave up her practice and moved to California, where she had family and the weather was better.

"I was very depressed, having given up my whole life, including a house I had

built on a lake," she said. However, in June 1999 she discovered a rare breed of dog, Xoloitzcuintli or Mexican hairless. Xolos were popular with the ancient Aztecs, who believed the breed had healing powers.

Because they have no fur, the dogs generate heat to stay warm and are hot to the touch, like a heating pad. When Nancy put her hand under her friend's Xolo, she found the pain in her wrist was relieved.

At the time Nancy was using a microwavable heating pad on her neck almost constantly. She realized she could replace it with a live, no microwave "hot dog." Her first Xolo was named Toaster.

Toaster has changed her life, she said. No longer does she have to go to the



Pink likes to help with office work.

Gardening Provides Way to Escape

by Deborah Wallace, Camarillo, California

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The requests for Xolo dogs led Nancy to apply for non-profit status so she could start asking for help breeding and sponsoring the dogs for applicants who could not afford these expensive dogs. She filed under the name Xolos for Chronic Pain Relief™ (X-CPR). Visit www.PawsForComfort.com for details.

Can-do Attitude

One of Toaster's pups is a female who almost died shortly after birth. Named "Pink" for her birth color, she walks (and runs) on three legs. Pink is completely hairless, so is "hotter" than Toaster, said Nancy.

Pink is also a certified service dog, and loves retrieving, able to distinguish between four different TV remotes, according to Nancy. The dogs recognize over 115 words, most of which are commands. Pink even retrieves Nancy's cell phone when it rings. In addition, Pink pulls off sweaters and socks, and can pull a blanket up over someone.

She loves picking things up off the floor, said Nancy. She picks up credit cards, coins, and papers. Her "never give up" spirit helped when she couldn't get under a paper on a concrete surface. After repeated tries, "she licked the paper and it stuck to her tongue, and then she grabbed it and excitedly brought it to me."

What attitude could be more helpful for someone with a chronic health problem?

New Sense of Purpose

Toaster was also the inspiration for a line of greeting cards to encourage people with chronic/terminal health conditions and their caregivers.

Nancy launched the cards in 2005 and is now selling them over the Internet and in gift shops.

In the nearly 10 years that I've had chronic pain—through contracting CRPS in 1998 and unrelenting migraines in 2005—I've found great relief in gardening.

When tending to our small yard I generally become lost in another world, one free of pain. Even on the "bad days" a few minutes with the plants keeps the pain at a distance. When I am bedridden, my pain is greater and depressing.

Also, the feelings of accomplishment I gain from gardening provides needed value to my life, a sense of worth that I abruptly lost when I was first diagnosed and was no longer able to work.



Recently, I discovered a helpful way to gain relief from pain when traveling by car. The addition of a car seat heater (portable at the moment, but soon to be built in, I hope) has greatly improved my car travelling ability. Trips away from home have increased in number and distance, providing yet another "emotional pain escape."

I hope these little discoveries for my own pain relief can be helpful to others in their search.

This business has given Nancy a "sense of purpose," she said, because, "One of the most devastating side effects of FMS/CFIDS for me was the loss of identity." The business combined her professional experience as a therapist with her personal experience with a chronic illness, and "gave me a way to help others again, because that's in my blood."

The greeting card business, inspired by Toaster, has given Nancy a renewed sense of purpose and a way to help others again.

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Learning New Ways to Move

by Sally Price

Jackie Mason's six-week experience with acute shoulder pain was severe enough to make her fear that she would have to give up her job, ending her 22-year career as a computer systems architect.

In desperation, she tried physical therapy, chiropractic, massage, and medication, but nothing helped. Then she learned about the work of Dr. Moshe Feldenkrais, who had developed a method of teaching people to move more efficiently.

"In one session, I was pretty much out of pain," Jackie said. That session consisted of "moving me around on a table...finally at one point I felt something give. I think my brain got a message 'you can relieve these muscles' and that's what it did."

Jackie, 49, of Nevada City in northern California, trained for four years in the Feldenkrais style of addressing movement patterns. After working with a physical therapist and discovering she was really gifted at teaching the Feldenkrais movements, she started her own business, "Movement for Life." Jackie is currently seeing about 30 clients a week. She teaches a "movement class" on a local television access station and on the Internet at www.movementforlife.info.

Jackie recently spoke to a local ACPA support group. She said she has worked with people who have had chronic pain for years.

After one to five months of practicing movement awareness exercises, they experienced great pain relief.

Efficient Movements Help Muscles

What she does, she explained, is work with people to make them more aware of how they move in everyday activities. With her guidance, they begin to practice more efficient ways to move, meaning they're using fewer muscles. "Their brains are changed by the movements," she said.

In Jackie's experience, 80 to 90 percent of people in chronic pain are stuck in movement patterns that are overusing their muscles and continuing their pain. "It's a big transition in thinking," she said of Feldenkrais. "We've all been taught to try harder. This is about doing less with your musculature so you can do more."

In the training, people relearn how to move as they did when they were much younger. This includes new ways to balance and sit. "When we sit, our pelvis is immobilized and starts other organizational problems with our structure," she said. "Cultures that squat don't have these problems." In Feldenkrais, people learn how to sit balanced by rolling their pelvis forward to rest on their sit bones, she said.

Jackie's enthusiasm for Feldenkrais is endless. She said, "Just because you're in your 60s or 70s you don't have to sit in a chair. You can have the movement you had in your 20s." For more information, go to <http://feldenkrais-method.org>, www.feldenkrais.com or Jackie's own web site at www.movementforlife.info. | TOP |

Painting Through the Pain

by Alison Conte and Sally Price

Romona Johnson, 44, of Tampa, Florida, suffers from Reflex Sympathetic Dystrophy (RSD), a neurological disorder characterized by severe burning pain, fever, chills, and numbness. For years, she dealt with her pain by painting.

Romona painted with acrylics, using colors to create abstract art that expressed the pain she is feeling. "Painting relaxed my soul. When I was going through a tough time, I painted, and I was distracted from the pain," she said.

According to a recent article in the *Tampa Tribune*, RSD kept Romona from employment and from swimming and shopping, two of her favorite activities. When she is unable to sleep through the night, she paints.

Her favorite tools are not paintbrushes but plastic forks, straws, and plastic shopping bags, which she uses to spread paint around the canvas. Her subjects vary, from abstract designs to nude human figures, and can be inspired by the Florida landscape or stormy weather. "A pleasurable activity, such as painting, can help people with chronic pain and simultaneously provide them with a distraction and a way to express what they are feeling," she said in the *Tribune* article.



Lately, increased pain has forced her to discontinue the painting that was so important to her, but she encourages others with pain to try it. "Art is a way to express what one feels in ways that words do not express," she said. | TOP |

Your Role in Medication Safety

Medications can help people with pain to function more fully and have happier, more productive lives. Yet, as long as there have been strong medicines for pain, there have also been people who would abuse those medications. Today, with stories of drug abuse and diversion a staple in the media, medication safety is more important than ever to all of us.

“The number of people legally taking prescription medications, and the number of medications they take, is increasing rapidly,” said Dr. M. Bud Lateef of Pittsburgh. An interventional pain management specialist who treats disorders of the spine, neck, and back pain, Dr. Lateef also develops products to ensure medication security.

“The days of storing medicines in the bedside drawer or medicine cabinet are over,” he said. “Drugs must be kept in a lockable container or cabinet, for privacy, safety, and security.” This is especially important for narcotic pain medications, insulin syringes, sleeping or anxiety pills, injectable medications, cancer treatments, anti-depressants, and seizure medications.

Pharmaceutical companies are working on new ways to make medications harder to abuse, but there are steps each of us can take every day to ensure the security of the medications that we use to manage pain. Here are some of them.

Keep your medications in a secure location. A medicine cabinet may not be the best place to store full vials of your medications. It is too easily accessible to visitors, workers, and others who may be tempted to take some of your medications. In addition, exposure to heat and moisture can cause medications to lose effectiveness. Try putting just a day’s dosage at a time in an easy-to-reach location and storing the remainder in a locked drawer or other safe spot.

Keep track of your medications.

Do you seem to be going through your prescriptions too quickly? If so, someone may be diverting a portion of your medication without your knowledge. Keep a count of pills and note when a prescription should be due for refilling.

Never share your medications.

Each person will respond to medications differently and many drugs can interact with medications already being taken. Helping a friend by sharing your pills can do him or her harm you never intended.

flushed away, but others need to stay out of the water supply. For greater safety, take unwanted medications out of their containers and mix them with used coffee grounds or used kitty litter. Then they can be disposed of in the trash. You also may ask your pharmacist about drug-take-back programs in your community. Information on the proper disposal of prescription drugs can be found at <http://www.whitehousedrugpolicy.gov/pda/022007.html>.

Try putting just a day’s dosage at a time in an easy-to-reach location and storing the remainder in a locked drawer or other safe spot.

Dispose of unwanted medications safely. Ask your doctor or pharmacist how to safely get rid of medications you do not plan to take. Some may be

Keeping medications safe and available for those who need them is everyone’s responsibility. With just a little effort, you can do your part to ensure that these drugs do only the good they were intended to do.

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Recent Advances in Pain Treatment – Part Two

by Steven Feinberg, MD

New developments in pain medications were discussed in Part One of this article, published in our Fall 2007 issue, available at www.theacpa.org.

Pros and Cons of Implantation Technologies

The technology and equipment for spinal cord stimulators and implanted pumps continues to improve. The manufacturers claim wider and better coverage and there are now rechargeable batteries, lengthening the time between surgical replacements. However, the technology remains expensive. Some medical professionals question the long-term gains and don't feel the technologies have been adequately proven beneficial. Proponents note evidence of cost savings over time although long-term data on lasting effectiveness is lacking.

Ziconotide (Prialt), administered by an implanted pump, is a therapeutic option for treatment of severe chronic pain in persons who have exhausted all other agents, including morphine by an implanted pump, and for whom the potential benefit outweighs the risks of serious neuropsychiatric adverse effects and of having an implanted device. This drug is not benign and before it is utilized, careful consideration should be given to the benefits versus potential negative side effects.

Hyperbaric Oxygen Shows Promise

Hyperbaric oxygen (HBO) therapy recently has shown promising results for some chronic pain syndromes but its use is far from proven. Several authors claim HBO is a reliable method of treatment and may be beneficial if appropriate persons are selected. Further research is required to identify the best treatment protocol, the cost/benefit ratio, and the safety of HBO in chronic pain management—and whether it actually works.

Functional Magnetic Resonance Imaging

While still in its infancy in the research lab and not yet ready for clinical practice, Functional Magnetic Resonance Imaging or fMRI offers hope for people with persistent pain.

Experts believe that fMRI can be used to show people what areas of their brains are activated when they're in pain. They could then be taught techniques for turning off, or at least turning down, their brain-initiated pain. As a treatment fMRI is similar to biofeedback, helping people with pain associate abnormal physical functioning (like muscle tension and constricted blood vessels that they may be able to learn to control) with signals, like sound or lights.

An interesting article on this subject, *The Strain in Pain Lies Mainly in the Brain*, by Sean Mackey MD, PhD, Director of Stanford University's Pain Management Center, can be found at <http://paincenter.stanford.edu/research>.

Neurofeedback (EEG Biofeedback)

One case report and a case series have reported that chronic pain can be reduced through electroencephalogram (EEG) biofeedback (also known as neurofeedback). It has been used to teach people with chronic pain to decrease the type of brain activity associated with pain and increase the type of brain activity associated with relaxation to reduce their pain. But controlled studies showing that this treatment is more effective than placebos have not yet been performed.

Lumbar Disc Replacement

There continues to be great interest in surgical replacement of lumbar discs. It has been widely used in Europe and is becoming more popular in the United States. There are strong proponents who

tout its benefit while others question its relative effectiveness and long-term efficacy compared to rehabilitation programs.

The Biopsychosocial Model of Functional Restoration

One of the “new” changes in pain treatment is really very old, well-researched, and well-established. It is as much philosophical as anything else. There is a growing rebirth and revitalization in pain treatment of the biopsychosocial model and the concept of functional restoration.

The traditional approach, termed the biomedical model, views pain as being directly caused by a specific injury or disease. Treatments are designed to correct physical pathology or to cut or block the pain pathways either by drugs or invasive procedures such as surgery or nerve blocks. While this model seems to work with acute and some chronic disease states, these approaches often result in inadequate pain relief and unacceptable levels of disability that persist well after the original injury has stabilized or healed. There are also side effects associated with all of these treatments that may actually require additional treatments and in some instances result in even greater pain.

The biopsychosocial model uses a functional restoration approach. It recognizes that pain is ultimately the sum of a person's:

- * Medical condition
- * Psychological state
- * Cultural background/belief system, and
- * Interactions with their environment such as the workplace, home, disability system, and medical providers.

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There is a shift of health responsibility from the doctors and therapists to the person.

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In the biopsychosocial model the focus is on the person, not the disease or physical pathology. Appropriate treatment in this functional restoration model includes assessment of the person's dynamic physical functional status. Along with traditional tests for strength, sensation, and range of motion are measures of what the individual can and cannot do functionally in terms of activities of daily living and work-related functions.

The assessment reviews psychosocial strengths and weaknesses including an analysis of the individual's support system. It also includes efforts at education of the individual and family members along with expectation management, functional goal setting, ongoing assessment of the individual's participation and compliance, compli-

cating problems, and progress toward achievement of goals.

There is now evidence from a number of controlled trials that self-hypnosis training, one of the components often used in biopsychosocial treatments, can reduce pain severity in some (but not all) individuals with chronic pain, and that these reductions can last at least 12 months (the length of follow-up from these studies). Even though not everyone reports a long-lasting reduction in their pain with this treatment, the majority report that once they learn self-hypnosis techniques, they can use them to obtain short-term reductions in pain that last for hours.

Functional restoration and pain management skill training includes a focus on education, a de-emphasis on passive

therapies, with importance placed on a home exercise/self-management effort. There is a shift of health and well-being responsibility (locus of control) from the doctors and therapists to the person. A substantial body of research has supported the benefits of this approach not only in pain reduction but physical and emotional functioning. This also results in less utilization of health care with few, if any, adverse events. *(Editor's note: This is the pain management strategy the ACPA has taught for more than 25 years.)*

Dr. Steven Feinberg, Psychiatrist and Pain Medicine Specialist, evaluates and treats patients with complex cases in his Palo Alto, CA office.

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Track Pain Through Online Health Record

NoMoreClipboard.com, an online Personal Health Record, now includes a free pain management module from Relieffinsite.com. The daily pain diary and helpful graphics help people to record pain location and intensity, capture symptoms, and track medications.

NoMoreClipboard allows you to store health information such as allergies, medications, and medical conditions in a secure online environment, monitor your progress over time, and transfer data to selected physicians and healthcare providers. For more information go to www.nomoreclipboard.com or www.relieffinsite.com.

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Just What is Evidence-Based Medicine?

by Jennifer Christian, MD, MPH of Webility Corporation, and ACPA Board Member

Evidence-based medicine is a new concept that physicians, legislators, and insurance companies are using to decide how to provide health care. It may strongly influence the way you receive pain relief.

The best short definition I've seen for evidence-based medicine is Dr. David Sackett's: "Evidence-based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients.... integrating individual clinical expertise with the best available external clinical evidence from systematic research."

However, the phrase "evidence-based medicine" has also become a buzz word, and like many hot topics, the term has been distorted and misused.

Evidence-based medicine involves evidence derived from scientific research, but people who do not know much about the scientific method often have unrealistic expectations about how the scientific community does its work. For example, it is understandable but incorrect to assume that:

- * All the important questions/issues in medicine have been researched
- * The research that has been done is good and has shown clear results
- * Most doctors know how to determine what all the accumulated medical evidence on a particular topic actually means
- * The results of the latest scientific research are generally available to clinicians
- * Those clinicians can simply look up what to do and do it!

The Not-So Scientific Method

Scientific insiders have always known that the scientific method is a rather crude attempt to pin down the messy thing we call reality and put it in a neat little box. In actuality, scientists take scientific "facts" with a grain of salt.

When I went to medical school, we were taught that 50 percent of what medical science knew then as truth would be proven false within 10 or 20 years. That's still true today. It's best to think of medical science as an on-going series of successive approximations or models of "reality," each more accurate than its predecessor.

In order for research to be done someone must want to do it and someone must pay for it. So in many areas, there hasn't been any research at all. If an issue hasn't been studied widely, as is the case with chronic pain, there will be little "scientific evidence."

Thus, it is unrealistic to expect that the only medical treatments that will be approved or should be prescribed are those supported by scientific medical evidence—particularly if you define "evidence" as established and "settled" research results.

Experts say that only about four percent of all types of medical treatments delivered in the U.S. today have a solid evidence basis. (A slightly rosier fact is that about half of U.S. residents receive appropriate care, because the relatively few treatments that are the most commonly employed have been scientifically tested for safety and efficacy.)

Developing Theories without Evidence

The basic idea of the scientific method is to start with an assertion or a theory and then test it or compare it with another idea by observing, documenting, measuring, and comparing the results. First studies that scientists do are generally simple, quick, and rather crude. This is because funders of research look for promising early evidence before making the kinds of large investments required to support

a series of well-designed randomized controlled trials—the highest quality studies.

So, it is appropriate and correct for the first literature in a new area of inquiry to consist of case reports, case series, and case-control studies. You could call these "pilot studies."

What's not good is to accept these findings as "proven."

So, there's nothing actually wrong here, because this is how science works: until scientists decide to take a "rigorous" look at an area of life, and until major investments are made in the highest quality research studies, people simply do their best—they make up their own way, or imitate the way that others do it, or do it the way that "authorities" say is the right way.

Scientific Truths Come and Go

The wavefront of science is continually moving forward, but I like to think of scientific progress as the ocean lapping the beach during an incoming tide. There are waves crashing and rushing up and down on the sand—just as the latest scientific findings often seem to contradict each other or are proven wrong the next year. (The studies on the bad/protective effects of coffee/tea/caffeine and hormone replacement therapy are examples.)

There are also the great new drugs that are announced, only to have horrible side effects revealed a few years later (Vioxx, phen-fen, thalidomide). Naturally, this area is unstable and in constant flux—it's the breaking surf of science.

But hidden by the surf, the ocean itself is creeping up the beach—there is progress being made, and areas that

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used to be the tumbling surf are now calm water. For example, there is little dispute these days that smoking cigarettes causes cancer, that seatbelts save lives, what causes AIDS, or whether laparoscopic surgery leads to a faster recovery. But it wasn't long ago that each of these topics was fiercely debated.

Ongoing Clinical Reviews are Unrealistic

To make an evidence-based health care decision, physicians must do a lot of work: assemble all the available studies, assess each one's strengths and weaknesses, weigh them all against each other, see what they say as a whole, and come up with a reasonable overall assessment of what the evidence says you should actually do.

In medical school, we did not learn much about how to read medical articles critically. However, after medical school, I went to public health school and studied biostatistics and epidemiology courses, learning to identify the falseness and audacity when I heard it.

But I still defer to experts in evaluating research design. It's simply ridiculous to expect every practicing clinician to have this level of expertise and to have the time to do it for themselves.

In life, people have to make decisions using the best data currently available, as insufficient and imperfect as it may be.

Professionals in other fields rely on fragments of information and incidental observations all the time, to run investment firms, election forecasts, and even the federal government.

Seek Experienced Care, Follow Guidelines

When treating chronic pain, a doctor who's really trying to do the right thing will seek and use the best available aggregate evidence. This is probably not the "newest" evidence based on a single study because that study is still in the "scientific surf."

Most doctors have not been trained to evaluate the quality of accumulated

scientific evidence—and the quality of the best available evidence is rarely very good. And, too many doctors simply prefer the treatments they are familiar with and have used with some success.

To those seeking to follow the best course possible, I strongly recommend that:

- * You select doctors who pride themselves in following evidence-based guidelines whenever they are available, and who have enough practical clinical experience to make wise recommendations to you.
- * You use common sense to determine if a treatment is actually working for you and helps you function better. If a medication is not helping you *do* what you want to *do*, and *be* the kind of person you want to *be*, then it's not working, even if you say you "feel better." If your medication or treatment regimen as a whole makes you more able to function in everyday life, then it is working.

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The Maze of Pain CONTINUED FROM PAGE 1...

Much of what will help you through the maze could be considered unusual: biofeedback, acupuncture, yoga, medications, exercise, diet, stress management, individual and family counseling, alternative therapies, and most importantly, personal involvement. So we need to be well-informed consumers, and learn about each treatment before making decisions. I hope you will keep an open mind when traveling through this maze of twists and turns, as you make the transition from patient to person.

The ACPA is currently seeking funding to develop interactive units called *The Maze of Pain*, based on the *ACPA Ten Steps from Patient to Person*. We hope to provide a guide through this complex maze, a guide that will help you improve the quality of your life and reduce your sense of suffering by increasing your understanding and knowledge of pain management skills.

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New ACPA Groups

Welcome to our new groups and facilitators.

Laurie Vaulker
Goodyear, AZ

Katie Frazer
Sun City West, AZ

Shelly Henson
Sun City West, AZ

Ann Kilby
Tucson, AZ

Kathleen Leonard
Tucson, AZ

Emilkis M. Marrero
Bell, CA

Ann Barnes
Lakewood, CA

Nora Silva
Norwalk, CA

Lee Westerlin
Norwalk, CA

Kelli Tice
San Jose, CA

Angela Greg
Whittier, CA

Dana King
Wilmington, DE

Debbie Edwards
Cape Coral, FL

Patrick Goertz
Wichita, KS

**Ernest Merritt and
Jane Avery**
Saco, ME

Lauren Blumer
Jackson, NJ

Sheila Netz
Grand Forks, ND

Mary Merden
Wisconsin Rapids, WI

ACPA Update

Catching up with the Board

by MaryAnn Farrell, Regional Facilitator

On October 20, 2007, I attended the ACPA annual full board meeting in Pittsburgh to give my input as a member of the ACPA, as a support group facilitator, and as the Regional Director of Western Pennsylvania. I was impressed overall with the board's knowledge and willingness to be available to all members and hope that my presence there properly represented us all.

Since the ACPA has grown so much over the past 25 years, our needs and resources have grown as well. Now serving on the board are 18 people: professionals in public relations, law, business, and finance along with physician specialists in pain management, anesthesiology, and emergency care as well as nurse practitioners, and pharmacists.

To me, this group seemed to care very much that ACPA members are able to live well as fulfilled persons, not patients. A few questioned me about my support group, asking how often we meet, what we do, and "Did I ever have special training to be a facilitator?" To that last question I smiled and replied, "I use the ACPA Facilitators Guide, but much of what I learn is through my life experiences and those of my fellow group members."

At the board meeting I learned a lot, gave my opinion (when asked) and concluded that the board is continuing to work well with members and support groups, often through information on the ACPA Web site.

As for public policy, most of our board members do exhibit an understanding of life with chronic pain. They will continue to share this with the media, employers, and veterans groups, as well as fight against disparities in pain care. Because I lived in a rural area for 14 years, I became acutely aware of the lack of understanding of among health care providers to those specific populations.

The board certainly understands our ACPA mission of moving from patients to persons, as well as how to support our family members. In 2007, the board worked hard to make the health care community—and the public—aware of our individual and collective issues, struggles, successes, feelings of isolation, frustration, and more. I see that that change is happening, though slowly.

Real Women, Real Pain

The International Association for the Study of Pain is launching a new campaign, "Real Women, Real Pain; Global Year Against Pain 2007-2008."

According to the IASP, chronic pain affects a higher proportion of women than men around the world. Unfortunately women are less likely to receive treatment than men, due to societal and cultural norms and economic and governmental barriers. Drawing attention to this global issue is a first step toward reducing women's pain and suffering.

IASP members and chapters will be organizing various programs and events to raise awareness of pain conditions affecting women and highlight the disparities between genders. A media campaign will seek to educate the public, healthcare providers and government leaders/agencies about these issues.

The ACPA joins with the IASP in working to reduce the pain and suffering of women worldwide. To learn more, go to <http://www.iasp-pain.org>. | TOP |



ACPA Chapters on ABC News Website

Who thought that living with chronic pain could make you famous? It happened to ACPA chapter members in New Jersey and Massachusetts last December.

Pat Merritt is New Jersey Regional Director and facilitator of the Morris & Warren County New Jersey Chapters of the ACPA. She told us how on Dec. 10, 2007, a producer from ABC News met with chapter members to work on an online network project focusing on chronic pain. The website “On Call Plus” features educational and resource information on several conditions including diabetes, breast cancer, and now chronic pain.

“Our group was asked to come up with questions for the medical specialists treating chronic pain. These ranged from medication usage and side effects to surgery, activity tolerance, and coping with feelings of depression and sadness. What emerged from our group was a sincere desire to learn how to better cope with chronic pain,” said Pat.

“As a facilitator, I was honored by the group’s openness and honesty. Not only were we tickled pink to be in front of the cameras but we came together with a focus of helping others. And for many of us, including myself, the experience gave me a profound sense that by sharing my personal experiences, my pain can contribute to society in an influential and positive way.”

The Arlington, Massachusetts (Boston-area) Chapter of the ACPA also got a chance to be “on-camera talent” for a day.

“ABC News came to our usual meeting space with their lights and cameras on Dec. 18, 2007, and 15 of our members came ready to share their experiences with chronic pain. Each of us got a chance, on camera, to ask our most pressing questions about pain that we



At left, Pat Merritt prepares for her moment in the spotlight. Above, the Arlington chapter discusses questions for ABC News’ medical experts.

would want an expert to answer,” said Cindy Steinberg, New England Director and Arlington, Chapter Facilitator. “Our questions covered a broad array of topics ranging from information on treatment options like implantable nerve stimulators and nerve blocks to questions about specific pain conditions such as fibromyalgia and RSD.”

“We also were asked to participate in small group discussions about life with chronic pain for a Round Table Discussion feature,” Cindy said. “We were given questions such as ‘What advice would you give to someone who just found out their pain will be chronic?’ ‘What is it like living with a hidden disability?’ and ‘What has been your experience with doctors?’ and asked to discuss them on camera for about 10 minutes. It was a great opportunity to give others—who may not have the benefits of being part of an ACPA support group—the wisdom and advice we have developed over months and years of meeting together.”

View “On Call + Pain Management,” on www.abcnews.com. Select the health tab for tips about living with pain. The ACPA groups’ questions are included, with answers provided by various pain experts. Watch for the Round Table Discussion to appear soon.

The Chronicle is published quarterly by the American Chronic Pain Association.

We welcome essays, poetry, articles, and book reviews written by people with chronic pain or their families.

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Book Reviews

The Chronic Pain Care Workbook

By Michael J. Lewandowski, PhD

Reviewed by Samantha Nagy,
ACPA Michigan Regional Director

I am extremely happy that I read this book. Dr. Lewandowski kept me intrigued, and coming back for more. Each chapter holds a wealth of useful information. Each time I set the book down, I found myself taking a close look at how I've been handling my chronic pain and how I could use the ideas from this book to help in my journey from patient to person. This is a very well-written book that is very easy to read and to understand.

Because the book is written in a workbook format, it's interactive and personalized. After completing the exercises and filling in your scorecard, you are able to create an individualized pain management plan based on your own needs. That's great because we all are unique, with different needs, and different goals.

Most of Dr. Lewandowski's thoughts and ideas mirror those of the "Patient to Person" manual. He is aware that there is so much more to living with chronic pain than just dealing with the pain itself. By reading this book, you will learn how behavior can affect pain and also those around you. I was able to assess my relationships with friends and family and learn where I should focus my attention to have healthier relationships. I also learned that by not working with my doctors as a team, I am probably not getting the most out of my medical care.

The book reveals the biological, psychological, and social effects on

chronic pain. When it is broken down in this way, you may find it easier to assess the triggers of your pain.

The Chronic Pain Care Workbook
by Michael J. Lewandowski, PhD.,
New Harbinger Publications, 240 pages,
[http://www.newharbinger.com/
contributorinfo.cfm?ContribID=407](http://www.newharbinger.com/contributorinfo.cfm?ContribID=407)

Understanding Pain

by Harry J. Gould III, MD, PhD

Reviewed by Dave Duhrkoop

This book is for readers who want a more advanced understanding of pain.

The book is written by a doctor for medical personnel, nurses, and others who are already well versed in the psychological and psychological aspects of chronic pain. Some understanding of general chemistry, anatomy, and psychology would be a definite help to any readers interested in this publication. I would not recommend it for anyone who has not already been introduced to pain system pathology.

Still, this book has something to offer those who have less advanced studies. The author's discussion of the chemical and clinical aspects of chronic pain is plain enough. Dr. Gould has taken great care to make this writing more than just a clinical study. He has, in a fact, made some very abstract knowledge for the professional into a clean and tidy "this is how it works" methodology for his readers. This is not an exposé on how to treat chronic pain but an in-depth study of the incredible systems that seek a balance to the pain sufferer's plight.

Understanding Pain; What It Is, Why It Happens, And How It's Managed, by Harry J. Gould, III, MD, PhD, published by: ANN Press (American Academy of Neurology), 2007

Living Well With Chronic Pain

by Jude Willhoff

Reviewed by Samantha Nagy,
ACPA Michigan Regional Director

I was drawn to this book because the author, Jude Willhoff, has chronic pain and has personally experienced what her audience is going through. This book is very well written, easy to read and understand. I learned a lot from reading this book, mostly about a different treatment approach. When Ms. Willhoff was telling of her experiences with the chronic pain, it felt very familiar.

Willhoff shares her journal entries throughout the book, which made it a very personal reading experience. I also really enjoyed the quotes at the beginning of each chapter. She tells how she and others with chronic pain overcame their pain.

I would recommend this book to anyone with chronic pain and will be passing it around my group. I think there is a lot of information in this book that a lot of us with chronic pain may not be aware of, particularly the benefits of journaling.

Living Well with Chronic Pain by Jude Willhoff, Thornton Publishing Inc., paperback, 208 pages, \$19.95
ISBN 1-932344-84-5,
[http://www.judewillhoff.com/
ChronicPain.html](http://www.judewillhoff.com/ChronicPain.html)

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Two Glasses of Wine



A professor stood before his philosophy class. Wordlessly, he picked up a very large and empty mayonnaise jar and proceeded to fill it with golf balls. He then asked the students if the jar was full. They agreed that it was.

The professor then picked up a box of pebbles and poured them into the jar. He shook the jar lightly. The pebbles rolled into the open areas between the golf balls. He then asked the students again if the jar was full. They agreed it was.

The professor next picked up a box of sand and poured it into the jar. Of course, the sand filled up everything else. He asked once more if the jar as full. The students said yes.

The professor then produced two glasses of wine from under the table and poured the entire contents into the jar, effectively filling the empty space between the sand. The students laughed.

“Now,” said the professor, as the laughter subsided, “This jar represents your life. The golf balls are the important things; your family, your children, your health, your friends, and your favorite passions. If everything else was lost and only these remained, your life would still be full.”

“The pebbles are the other things that matter, like your job, your house, and your car. The sand is everything else; the small stuff.”

“If you put the sand into the jar first,” he continued, “There is no room for the pebbles or the golf balls. The same goes for life. If you spend all your time and energy on the small stuff, you will never have room for the good things that are important to you.”

“Pay attention to the things that are critical to your happiness. Play with your children. Get medical checkups. Take your partner out to dinner. Play another 18 holes or go skiing. There will always be time to clean the house and fix the disposal. Set your priorities and take care of the things that really matter. The rest is just sand.”

One of the students raised her hand and inquired what the wine represented. The professor smiled. “I’m glad you asked. It just goes to show you that no matter how full your life may seem, there’s always room for a couple of glasses of wine with a friend.”

Editor’s note: We received this story via email, with no attribution.

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Thank You!

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A FACILITATOR IN LIMA, OHIO

We honor his committed work and dedication to helping people deal with chronic pain.

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Where Does It Hurt?

by Leslee Cox

Have you ever had a doctor say,
“Describe your pain to me?”
Right away I start to wish,
It was something they could see.

I never know just what to say,
When this is asked of me.
Is it like a toothache in my toe,
Or a headache in my knee?

Is it dull or sharp or stabbing?
Does it throb or only ache?
Does this happen to you all the time
Or just when you're awake?

Now, on a scale from one to ten,
Your pain you have to rate.
Ten's supposed to be the worst,
One's when you're feeling great.

Sometimes my pain's a fifteen,
Sometimes it's barely there.
Believe me when it's really bad,
I'm pulling out my hair.

You'd think with our technology
They could make a machine to see
What kind of pain and where it is
So they'd stop asking me.

Written by Leslee Cox, a patient at the Hennepin Faculty Associates Interventional Pain Clinic in Minneapolis. Submitted to the ACPA by Geri Ann Kubitschek, RN, BSN.

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 keep the ACPA alive and reaching out to even more people with pain. Thanks for helping us help others.

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