We all want life to be simple and uncomplicated. We seek simple solutions for any problem. But, if you are a person with pain, you know that life is not simple. When chronic pain becomes your constant companion, there is no quick, one-step solution to regaining control of your life.

Initially we believe that there will be a medication, a therapy, or a surgery that will allow us to go back to the life we knew before the pain. But it doesn’t take long for us to realize that the word “simplicity” is not part of living with chronic pain. The road is long and hard. Some days it is difficult to hold on to hope.

The last eight issues of the ACPA Chronicle have focused on individual skills that help us on our journey from patient to person. Each step provides us with an opportunity to improve the quality of our lives and reduce our sense of suffering. But it is imperative to realize that pain management is a complex set of skills, requiring a personal effort, along with appropriate medical treatment and support.

We need to take everything that we have learned about managing pain and apply to our lives each and every day.

I have met many people with pain who are desperate for a means to regain control of their lives. As we talk, I discover that they have tried a number of therapies and coping skills in an attempt to manage their pain—yet they did not get the desired results. Perhaps the problem is that they tried each one individually, rather than seeking a unified approach.

Think of chronic pain as a car with four flat tires. In an attempt to manage the pain we find a medication that helps, but it doesn’t deliver complete results. It may prove to be a complete, simple, no-hassle answer. We need something more; we can’t drive on three flat tires.

We need to take everything that we have learned about managing pain and apply to our lives each and every day.

CONTINUED ON PAGE 6...
Keeping an Eye on the Big Picture

P

eople who live victoriously with chronic pain share some common traits. They are determined people who are motivated by goals they set for themselves. They also keep a positive outlook by disciplining their thoughts.

When these people reached Step Nine on the journey from patient to person, they were ready to look at the total picture: how to live a normal life in spite of chronic pain. Looking back, they agree that Step Four: Setting Realistic Goals was the most beneficial step in their chronic pain journey.

Lorraine Fleury, who lives in Pollock Pines near Sacramento, California, says goal-setting was most helpful to her, especially after she became unable to work. “It forced me to focus on what I could do instead of what I couldn’t do. It has helped me to face each day with much more of a sense of purpose that I wouldn’t otherwise. Having a sense of purpose in my life has been vital to my well-being,” she says.

Lorraine has had chronic pain for 33 years, beginning at age 14. As she got older it got worse, despite treatments and surgery. She had plenty of reasons to become bitter and negative. But instead, she joined an ACPA support group and started working the steps.

“The group,” she says, “helped me to know that I was not alone and that the way chronic pain was affecting my life was not unique to me. That sort of freed me to get away from the judgment of it and get onto the business of dealing with it as it was.”

The first step of accepting the pain is to socialize and join a church group, hobby club, or an ACPA support group. “I look at my life as a half-full glass, work on acceptance, and cultivate a deeper relationship with God,” Lorraine says.

Nancy Fortner of Rio Vista, California, has been dealing with arthritic pain and fibromyalgia in a determined way for years. Like Lorraine, she found Step Four to be most helpful, although she sees all the steps as very important.

The first step of accepting the pain is to recognize when those negative emotions are building up strongly. “I take time out to breathe and affirm myself. I take time out for the day to meditate and to affirm to myself that I accept what is going on,” she says. Then she’s able to get into a harmony with what’s actually happening—that she is feeling intense pain and unable to do something she wants to do.

The most helpful members of Lorraine’s group were those who found humor in their situations and could laugh about it. “I was really helped by their example and learned to incorporate more humor into my life and into my chronic pain experience,” she says.

Nancy believes people with chronic pain often overlook the little things they could do to help themselves because they’re looking for big, overall solutions that don’t exist. “Taking care of something small goes a long way toward helping the bigger problem,” she says.

One little thing that helps a lot is “pre-emptive resting,” taking a break to rest before you get tired and push yourself into a pain flare. “Another little thing that keeps her thoughts positive is a pretty big thing: reaching out. Nancy has made it a habit to reach out to others who need help. She also remembers to be as kind to herself as she would to someone else in her situation. Finding new hobbies to enjoy is another ongoing activity.

Lorraine sees living with chronic pain as a huge challenge with no easy answers, affecting all aspects of life: financial, social, career, and family. “But,” she says, “I also see the importance of continuing to strive to make the most of my life despite chronic pain, because giving up would only make things worse.”

“I see that by making the most out of my life and doing my best, I can still have a rich and rewarding life in many, many ways. I see that chronic pain has made me much stronger, more understanding, more patient, and wiser than I was before and for this I am grateful,” she says.

Lorraine’s advice to persons new to chronic pain is to socialize and join a church group, hobby club, or an ACPA support group. “I look at my life as a half-full glass, work on acceptance, and cultivate a deeper relationship with God.”

The central and most practical thing I do to live with pain is to stay within the limits of my available energy—to stay within my ‘energy envelope.’ ” Nancy says. “So I schedule nine hours in bed every night to compensate for wakefulness.”

Lorraine points to keeping a daily journal and making to-do lists as two things that have most helped her to keep focused on the big picture over the last 10 years. “I do the journal on the computer so it’s easy to do, and it includes such things as what I did that day, medica-

tions, pain level, thoughts, and feelings,” she says. “When I read back over it, it really helps me get a sense of how I’ve made the most of each day. My morning to-do list helps me plan my day in as meaningful, and yet flexible, a way as possible.”

Keeping a positive outlook is most important to both women. Nancy says, “I have made it a habit to congratulate myself for the effort I am making whether or not I reach my goal. Giving myself ‘pats on the back’ in this way reminds me of what I have been able to accomplish and it keeps my outlook positive.

“I also remind myself that there is much in life for me to enjoy, be it something simple like my dog licking my nose or the grandeur of a sunset.”
Acupuncture is an ancient Chinese folk medicine based on the philosophic concepts of the Tao. Well-recognized and utilized for hundreds of years as a healing art for patients in many Asian societies, including Japan and Vietnam, it has now reached world-wide acceptance for medical treatment.

Acupuncture involves the stimulation of certain predetermined points on the skin through insertion of specially designed, solid, metallic needles. Acupuncture treatments can be used not only to alleviate acute and chronic pain conditions, but also for anesthesia and in the treatment of many other diseases.

There are some common side effects. Some people experience transient lightheadedness (possibly from seeing the needle), fainting (1 percent), bruising (5 percent), and persistent soreness for hours or days after the treatments.

Reluctant Patients Find Relief

Many people have found that acupuncture just does wonders for chronic pain. As it helps your pain, it can give you more energy, improve your sleep, and change your outlook on life.

Many people have found that acupuncture just does wonders for chronic pain. As it helps your pain, it can give you more energy, improve your sleep, and change your outlook on life. In addition, there are no medication effects to deal with.

Significant complications from acupuncture are rare, but these can include systemic bacterial infection or cellulitis from a contaminated needle, pneumothorax (punctured lung), and viral infections such as Hepatitis B or C.

Because the pain kept him from being in peak condition, he was prone to other injuries. He had been through numerous orthopedic surgeons and the usual diagnostic workups, as well as extensive physical therapy, medications, and spinal injections. All that gave him only short-term relief. He did not want to depend on medications, so reluctantly, he gave acupuncture a try. With the very first treatment, to his surprise, his back pain went away, his knees improved, and best of all, his game improved. He was happy, his team was happy, and his fans were thrilled.

Reluctant Patients Find Relief

Acupuncture helps at many different levels of pain. If you have an acute new problem, such as an ankle sprain, placing the needle correctly can take care of the whole patient. There are several styles of acupuncture and they all have their strengths. A doctor who does acupuncture will know which is best for each patient. You can also select an acupuncturist from the website of American Academy of Medical Acupuncture: www.medicalacupuncture.org.

Acupuncture is not difficult to perform. Modern needles are usually made of solid stainless steel and can be disposed of or reused after sterilization. Needles vary between one-eighth inch to five inches in length and from a fairly thin 26 to 36 gauge. To compare, a large gauge, like 26, indicates a very thin needle (a small hair’s breadth) and is usually drawn through a hollow 16 or 18 gauge needle, which would have a larger bore.

After exhausting all that traditional medicine had to offer, she decided to try acupuncture. A few sessions of acupuncture later, she had more energy, was sleeping better, had fewer aches and pains, was less depressed, and was able to exercise more. Her whole outlook on life had changed.

These two people offer two ends of the spectrum of chronic pain; most people with pain fall somewhere in between. But in my 12 years of practice, I have seen acupuncture help such a wide variety of people with pain, that it boggles my logical medical brain.

Many people have found that acupuncture just does wonders for chronic pain. As it helps your pain, it can give you more energy, improve your sleep, and change your outlook on life. In addition, there are no medication effects to deal with.

By most medical standards, acupuncture helps at many different levels of pain. It helps relieve inflammation and unblocks the flow of energy, thus helping the spine, the bones, the nerves, and the ligaments function more efficiently.

In addition, acupuncture will help internal organs, which in turn helps with sciatric pain. In cases like chronic fatigue syndrome or fibromyalgia, where the body’s immune functioning has been depleted over the years, acupuncture will also help boost it to greater effectiveness. Acupuncture also helps the emotional and mental component of chronic pain by releasing endorphins—the body’s feel-good chemicals—both locally and diffusely, which helps the body heal better and faster.

There are many scientific studies that prove the efficacy of acupuncture in cases of chronic pain. But the effects of acupuncture are really so varied and profound that a typical double blind research trial cannot do it justice.

As with any pain treatment, acupuncturists should be sure that they do not treat the symptoms and overlook a serious undiagnosed disease (such as cancer). This can prove disastrous since the underlying disease would progress unrecognized without appropriate directed treatment.

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Following needle insertion, there is additional manual manipulation to stimulate the acupuncture point (lifting, thrusting, twisting, or rotting). Some acupuncturists attach the needle to a low voltage battery, a procedure called electro-acupuncture. In either case, needles are left in for approximately 20 to 40 minutes and are then removed. Treatment frequency can be once a day or as infrequently as once every 7 to 14 days. A typical course of therapy is 10 to 20 treatments, but this varies among the practitioners.

Reluctant Patients Find Relief

A professional basketball player had experienced chronic back pain, as well as pain in his knees and feet for years. It was caused by patellar tendonitis. About mid-season, his back and knee pain were so severe that they restricted his playing time.

Because the pain kept him from being in peak condition, he was prone to other injuries. He had been through numerous orthopedic surgeons and the usual diagnostic workups, as well as extensive physical therapy, medications, and spinal injections. All that gave him only short-term relief. He did not want to depend on medications, so reluctantly, he gave acupuncture a try. With the very first treatment, to his surprise, his back pain went away, his knees improved, and best of all, his game improved. He was happy, his team was happy, and his fans were thrilled.

Reluctant Patients Find Relief

In another case, it was a 45-year-old woman who had increasing body aches and pains over 10 years. All her diagnostic workups were negative and her physicians told her it was “all in her head,” which she did not believe. They wanted to put her on pain medications, anti-depressant medications, muscle relaxants, and anti-inflammatory drugs. This was not the lifestyle she wanted, as she knew that she could not tolerate these strong medications.

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What is Integrative Medicine?

Integrative medicine combines knowledge from many therapies, doctors can treat chronic pain patients at different levels, and no one treatment alone. “We pay attention to nutrition, stress management, and health of the immune system with combinations of several different modalities,” says Dr. Chitnis. This way of practicing medicine can be more satisfying both to the physician and to the patient, she adds. “If a patient is seeing different practitioners for many different modalities, the left hand may not know what the right hand is doing.” To explore integrative medical services, look for a medical doctor who is trained in other modalities. If you consult other practitioners, check their credentials carefully, as these fields are new and providers are operating on varied levels of professional status and experience.

The American Holistic Medical Association (www.holisticmedicine.org) can be a good resource for information on integrative medicine.

Integrative medical services may include massage, counseling, Reiki, yoga, shiatsu, biofeedback, chiropractic, hypnosis, homeopathy, naturopathy, craniosacral therapy, the arts therapies, and Western medicine.

What to Expect From Acupuncture

When a person with a chronic pain disorder exhausts the doctors’ toolkits of oral medications, injections, implants, and possibly surgery, what else is there to relieve the pain? Acupuncture, a medical treatment that originated in China over 3,000 years ago, manages my activity- and vibration-induced cervical dystonia and shoulder impingement and calcification by controlling the pain, pulling, and spasms in the neck and increasing mobility.

Western medicine, including the American Academy of Pain Management, now embraces acupuncture for pain control; numerous insurance companies include an acupuncture rider.

The initial consultation is like many doctor’s visits. The acupuncturist reviews your medical records, test results, films, and any other data you feel is pertinent. The acupuncturist determines if he or she can help you with your chronic pain. If so, you both agree on a plan of treatment and you will have your first session.

Allow 20 to 40 minutes for a typical treatment and expect to pay about what you would for a massage. Dress comfortably. The procedure combines heat and the placement of pre-sterilized, disposable needles, the size of a filament or a hair, in specific points of the body to stimulate healing and relaxation. Results are immediate.

Obtain the person’s acupuncture license number. Be sure he or she graduated from an accredited U.S. college, taking graduate level work in acupuncture and oriental medicine with a minimum of 3,000 hours coursework. While I prefer a dedicated acupuncturist, you will find that anesthesiologists, internists, and chiropractors also perform some acupuncture. Avoid people who have learned acupuncture through a few hundred hours of online or long-distance coursework other than from NCCAOM.

If you decide to try acupuncture, proceed with caution in this unregulated field. Conduct telephone interviews prior to scheduling a consultation. Dr. Shen Ping Liang, LAc PhD of the Acupuncture Care Clinic in Houston, is a master practitioner. Dr. Liang is founder and chancellor of the American College of Acupuncture and Oriental Medicine in Houston, Texas. He recommends the following guidelines and questions for selecting a certified, licensed acupuncturist.

Select an acupuncture specialist or verify certification through the National Certification Commission for Acupuncture and Oriental Medicine (NCCAOM) by visiting their website www.nccaom.org. You can view a list of certified practitioners in your geographical area. (Editors note: You can also pick an acupuncturist from the website of American Academy of Medical Acupuncture. www.medicalacupuncture.org).

Obtain the person’s acupuncture license number. Be sure he or she graduated from an accredited U.S. college, taking graduate level work in acupuncture and oriental medicine with a minimum of 3,000 hours coursework. While I prefer a dedicated acupuncturist, you will find that anesthesiologists, internists, and chiropractors also perform some acupuncture. Avoid people who have learned acupuncture through a few hundred hours of online or long-distance coursework other than from NCCAOM.

Acupuncture does not hurt. Although it doesn’t cure all conditions, acupuncture provides relief from the symptoms of pain and induces a good night’s sleep. Administered properly, acupuncture produces safe, painless results.

R.B. Eckhardt is a writer who has facilitated ACPA groups in Texas. She has found relief from the pain of cervical dystonia and shoulder impingement through acupuncture.

Total Outlook CONTINUED FROM PAGE 1...

It is up to each of us to step back and look at the whole picture, at all the pain management techniques and treatments we have learned about. We need to choose from these and decide what we need to put in our other three trees. It is imperative that we determine what our needs and limits are as we begin our journey. It is possible to live a full life in spite of the pain. But we must seek the right combination of skills and medical treatments to move forward on the road of life. We are responsible for maintaining the wellness we have worked so hard to obtain, and build a brighter, meaningful future.

Don’t bother just to be better than your contemporaries or predecessors. Try to be better than yourself.

— WILLIAM FAULKNER
**Facilitator’s Forum**

**by Ginny Kelley, Facilitator of the San Mateo, California ACPA Support Group**

Starting and facilitating an ACPA support group is a lot like concocting a really great chicken noodle soup. It takes time!

**SOUP Step 1:** Begin with a good basic stock created from chicken, water, and vegetables.

**GROUP Step 1:** Begin with ACPA materials, handbook ideas, suggestions, and videos.

**SOUP Step 2:** Add some spices like salt and pepper.

**GROUP Step 2:** Add some speakers to bring new information to the group. (We have had speakers on guided imagery, Watsu water therapy, and mindful meditation.)

**SOUP Step 3:** Add a Secret Spice! Maybe curry or cayenne.

**GROUP Step 3:** Add your own Secret Spice! Each one of us has our own “spice” that makes us unique. Mine consists primarily of creativity and humor.

**And Now, Back to Our Recipe**

**SOUP Step 4:** Allow ingredients to simmer about 1 hour.

**GROUP Step 4:** Allow group to jell. It takes time for the nucleus of the group to form. People need time to get comfortable with one another and attend the meetings consistently.

**SOUP Step 5:** Remove cooked chicken from stock pot, and strain remaining mixture through cheesecloth.

**GROUP Step 5:** As the group jells, individuals begin to add their ideas and talents. This is when the group becomes interesting and productive.

**SOUP Step 6:** Make your soup surprising by adding beans,matzo balls or tomato paste along with noodles and chopped carrots. Simmer until done

**GROUP Step 6:** Your group will sometimes surprise you with the direction it takes. Listen and figure out what your members want and combine it with the ACPA philosophy and materials.

Much like the taste of good soup changes with each cooking, the dynamics of the support group also change. Some meetings are joyful, some are a little flat, and some are rather chaotic. However, all of the meetings are interesting, and all of them help our members in one way or another.

ACPA support group facilitators can send their essays and ideas for this new column to ACPA, P.O. Box 850, Rocklin, CA 95677.

**ACPA Update**

**Annual Board Meeting**

At the Oct. 22, 2005 board meeting, the ACPA board welcomed three new board members, Hilde Berdine, Jennifer Christian, and Claire Patterson. We also acknowledged the resignations of Greg Frazer, Jay Jackson, and Tsu Doong due to added responsibilities in their professional lives.

Bridge Calhoun was elected president, with Joanne Schneider as secretary and Daniel Gala as treasurer. Other ongoing board members are Diana Adams, Mary Jane Bent, Penney Cowan, Ed Covington, Steve Feinberg, Tomio Inomata, Nicole Kelly, Jen May, Chris Passero, Joan Tesla, Knox Todd, and John Williamson.

**ACPA Snapshot**

As of October 2005, the ACPA has:

- 452 support groups
- 4,912 members
- 600,000 to two million hits on the Web site each month

Some of our strongest accomplishments during the 2004-05 fiscal year were:

- Developing unique materials for self help and making them available to individuals and health care professionals
- Providing a broad array of resources through our web site
- Representing people with pain on educational and informational commissions
- Serving as a point of contact for more than 80 groups with an interest in pain
- Seeking a broader funding base to support our organization

**Time Out for Humor**

Creativity and humor can manifest themselves in various ways. It’s important to remember that even though chronic pain is serious, we shouldn’t take ourselves too seriously! Humor helps us lighten up. When I create a monthly calendar for each member, I try to add some fun to their lives.

My calendar for May displays lots of penguins, with one of them parachuting. It says: If penguins can fly, so can I. In October, I show a live and colorful hen sitting on a keg with lots of chicks scattered on the calendar. This message reads: Recipe for great chicken noodle soup. Step 1: Place chicken in pot of water—if only life came with better directions!

During good weather, my group has a monthly walk. Everyone wears a visor with our slogan: Chronic Pain Is No Walk in the Park.

**Public Outreach Extended**

In the last year, the ACPA continued to reach out to the public and increase awareness of the issues that face people with pain. We helped people understand their options following the withdrawal of nonsteroidal anti-inflammatory drugs (NSAIDs) in a booklet called “Options for Managing Pain.” We also co-produced “Making Sense of Pain Relief” a discussion guide to help people talk to their healthcare providers. Go to www.theacpa.org for information on obtaining these publications.

The ACPA is working with Organon/Ligand Pharmaceuticals to help doctors provide their patients with starter kits for managing pain. Other outreach programs in the works include a review of breakthrough pain, ulcer pain, the relationship between pain medication and constipation, and part two of “It Takes Nerve.”

**Pain in the Emergency Department**

Recently, the ACPA surveyed individuals who went to their local hospital emergency departments for pain relief. The survey was posted on our web site in September and October 2005. We received more than 250 responses, detailing why people with pain went to the emergency department, how they were treated, how long they waited, whether they received analgesics, and how satisfied they were with their visit. In the coming months, we will be analyzing the data and preparing a report. Look for an article in a future issue of The Chronicle, with follow-up research to come.

**Medication Coverage Fact Sheet**

If your drug isn’t covered by your prescription drug plan, what can you do?

Find out in a new Medication Coverage Fact Sheet from the Health Assistance Partnership. It describes, in simple and straightforward terms, some actions you can take to be sure your medication costs are paid for by your health insurance.

The first step is to find out why your health insurance is turning down your claim. You may also need to talk to your doctor about switching to a drug that is on the plan’s “formulary.” The fact sheet also explains how to request an “exception” and to file an appeal. You can download the fact sheet from our Web site at www.theacpa.org. For more information on health insurance, go to the www.healthassistancepartnership.org.

**Study Participants Sought**

Men and women cancer patients or cancer survivors on prescription pain medication are needed to participate in a clinical research study of an investigational medication. If you have cancer, or are a cancer survivor, are at least 18 years old and suffer from constipation due to your prescription pain medication, you may be eligible to participate in a clinical research study of an investigational medication for treatment of your constipation.

All study related clinic visits, medical evaluations and study medications will be provided at no cost to patients. Call the Patient Recruitment Call Center at 1-888-972-2180, Monday through Friday, 8 a.m. to 8 p.m. EST. To learn more, visit www.center-watch.com/constipation.
Board Focus: Bridget Calhoun

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

Bridget Calhoun took over as president of the ACPA Board of Directors in October 2005 and she is still getting used to the idea.

It was former ACPA president John Encandela who initially asked Calhoun to join the board in 2000, and she has served on the executive committee for several years. “I thought I was too busy to be on the committee,” she says, “But I quickly learned that everyone is too busy and so dedicated. I felt unworthy to be president, after only five years, but the board members have been very supportive and encouraging.”

Calhoun, MPH, PA-C, is assistant professor and chair of the Department of Physician Assistant in the School of Health Sciences at Duquesne University. She has involved her students in ACPA activities, taking them to Washington, D.C. for Partners for Understanding Pain events. She has also arranged to have ACPA materials translated through Duquesne’s English as a Second Language program.

Currently pursuing a doctoral degree in Public Health at the University of Pittsburgh in the Department of Infectious Diseases and Microbiology, Calhoun is completing her dissertation on the risk of arteriothrombosis in HIV-infected men taking highly active antiretroviral therapy.

She began her career in health care at the University of Pittsburgh Medical Center in 1992, working in transplant surgery. She continues to work clinically with HIV/AIDS patients on research projects at the University of Pittsburgh.

“Coming in contact with pain is inevitable for all of us,” says Calhoun. “I have had firsthand experience with AIDS patients and know that we need to encourage better understanding of pain for the public. We also need to further educate health care providers—starting with students and faculty—about proper pain management.”

“In the coming years I hope we will expand our mission to serve more people with pain and translate more materials to reach a broader audience. It is also important to recruit new board members with diverse talents in the marketplace, like information technology and finance. If we look outside the health profession we can incorporate people with new ways of thinking about an issue and expand our existing resources,” she says.

“Penney [Cowan] has good interaction with the key players in the field of pain management and legislation,” adds Calhoun. “The board will do all it can to offer her our ongoing support.”

Tips for Living with Chronic Pain

Modern technology—and old fashioned good ideas—have helped me manage chronic pain on a daily basis. It is my hope that at least one of these tips or products will help make you more comfortable, avoid flare-ups, or distract you from the pain.

Products:

- Telephone headset such as the ones made by Plantronics
- Obusforme portable seats and high backrests: These are lightweight, ergonomic, and easy to carry when you need a seat at the movies, theatre, symphony, school, car, train, or plane. This seat is a must for... 

by K.B. Edelhardt

Avoid things that cause muscle tension such as cold, noise, and negativity. Remember, scary movies may make you jump when you least expect it.

Do stay informed about your condition. Read newsletters and magazines from ACPA and the national organization for your disorder. Search the Web for additional information.

Communicate with your doctor, family, and friends.

Focus on what you can do. Pace yourself.

Reinvent yourself. Try different things, like new hobbies, hair styles, organizations, and volunteerism.

Follow the press conference, attendees had individual and group meetings with their state legislators. Nicole Kelly, past president, ACPA, my students, and I met with Rep. Michael F. Doyle of Pennsylvania’s 14th District and had an opportunity to describe the financial impact of chronic pain and the need for additional research. Rep. Doyle and his staff were welcoming and receptive to our comments and we hope he will sign on as a supporter of this important piece of legislation.

A passion of mine is to encourage better understanding of pain for the public. We also need to further educate health care providers—starting with students and faculty—about proper pain management.

In the coming years I hope we will expand our mission to serve more people with pain and translate more materials to reach a broader audience. It is also important to recruit new board members with diverse talents in the marketplace, like information technology and finance. If we look outside the health profession we can incorporate people with new ways of thinking about an issue and expand our existing resources,” she says.

“Penney [Cowan] has good interaction with the key players in the field of pain management and legislation,” adds Calhoun. “The board will do all it can to offer her our ongoing support.”

All in all, the visit to Washington was a great experience. However, as productive as the individual and group meetings were, there is still more to be done to gain widespread support for House Bill 1020. Penney Cowan and I and the entire ACPA board encourage each of you to become involved to the extent that you can. Please consider meeting with your Representative in his or her local office. If that is not possible, consider writing a letter or making a phone call.

We have almost 5,000 members.

- Imagine the impact of every ACPA member meeting with his or her Representative.
- Imagine the impact of every ACPA member writing a letter.
- Imagine the impact in the lives of the 50 million Americans who experience pain.

For more information about the National Pain Care Policy Act and pain advocacy, please visit the Partners for Understanding Pain web site at www.understandingpain.org. We need as many people as possible to rally for this bill!

Students Join Trip to the Hill

by Bridget Calhoun, President, ACPA Board of Directors

On September 13, 2005, I had the pleasure of traveling to Washington, D.C. with colleagues from Partners for Understanding Pain and four of my physician assistant students from Duquesne University. The purpose of our trip was to encourage our Representatives to support House Bill 1020, the National Pain Care Policy Act.

Approximately 35 people, representing several pain-oriented organizations, attended a press conference which featured Penney Cowan, ACPA executive director; Congressman Mike Rogers (Michigan), the Bill’s co-sponsor; Maggie Chesnut, coordinator of ACPA’s Growing Pains group, and entertainer Jerry Lewis, who is now living with chronic pain. As a temperament who suffered with pain, Maggie did an excellent job articulating the difficulties and delays in diagnosis she had with the healthcare system. She was incredibly inspirational and reminded us why we dedicate our time to advocate for those living with pain.

Students from Duquesne University joined organizations of ACPA and Partners for Understanding Pain to present this vital legislation.

Penney Cowan emphasizes the importance of House Bill 1020, the National Pain Care Policy Act.
Talking Magazines
by K.R. Eckhardt

Has your chronic pain disorder hindered your ability to enjoy reading magazines and books?

Once I read five or six books a month and numerous magazines while enjoying an active career and social life. After contracting cervical dystonia coupled with shoulder impingement, I tried to continue, experimenting with editor’s desks, pillows, and other items designed for a more comfortable reading position. They didn’t solve my dilemma of neck alignment. Furthermore, the reader’s tools frequently required that I hold onto at least one side of the book or magazine.

Though books on tape are a popular alternative, I recently discovered audio-taped, unabridged magazines from Choice Magazine Listening, a non-profit organization providing articles, essays, fiction, and poetry from over 100 publications free of charge.


To have cassettes mailed to you, contact CML at 1-800-724-6423, www.choicecassiettlistening.org, or choicemag@aol.com. The organization will send you the Library of Congress single-page form to register for the program and a special playback recorder.

Once you’re registered, the Library of Congress will send a current catalogue with ordering and no-cost shipping instructions from The National Library Service for the Blind and Physically Handicapped, www.loc.gov/nls.

Books include non-fiction, fiction, young adult, Spanish, and best sellers. You can also order Reader’s Digest in English, Spanish, German, and French.

Our physical activity may be limited due to chronic pain, but our minds can be active, thanks to these free magazine and book listening programs.

Chronic Pain and the Family: A New Guide
by Julie K. Silver, M.D.

Reviewed by Emily Holzberg, MS, OTR/L

This book is an excellent general overview on how chronic pain affects the entire family. It is written with the perspective of a medical doctor specializing in pain treatment and the author uses basic layman’s terms to reach a wide audience. There is a long explanation of the problems associated with chronic pain and a relatively short list of potential solutions or treatment options, but this guide is an excellent starting point for an individual and/or the family in researching chronic pain. There is also an extensive list of resources and suggested reading in the appendix.

Dr. Silver discusses pain behaviors as maladaptive ways of dealing with pain. If the family responds too much, they can reinforce disability and inactivity. On the other hand, a limited response can cause the individual in pain to feel hostility and resentment. Strategies are provided for the person in pain and family members to eliminate these behaviors and facilitate effective communication.

Often the fear of pain can be more devastating than the actual pain itself. There is a fear of losing the ability to deal with the pain with dignity. Understanding the meaning and prognosis of the pain can bring solace.

Dr. Silver reviews how children at different ages will respond to the chronic pain of a parent or themselves. She gives strategies for how much information to share about the disorder and how to help ease fears.

Members of the extended family might be afraid to offer too much help because they don’t want to reinforce negative pain behaviors. People with pain should specify just what kind of help they need; otherwise friends might give up offering simply because they don’t know what to do.

Dr. Silver discusses the biological similarities between pain and depression including lack of serotonin and noradrenaline. There is a high correlation between chronic pain and suicidal ideations that should not be ignored.

Dr. Silver encourages the reader to rely on support systems to help cope with pain. Accepting loss and taking responsibility for how you respond to loss are noted as important steps to recovery, but few concrete strategies are offered on how to go about this.

There is a short list of treatment options for pain including injections and modalities. This is a weak section of the book and I encourage the reader to explore this more in-depth in the recommended reading listed.

Dr. Silver also discusses how you can safely incorporate complementary and alternative medicine into your pain control regimen. She encourages patients to notify their chronic pain doctor about any such treatments and take advantage of their skills, abilities, and the latest technology to evaluate a problem. Once a clear diagnosis is made, it is safer to pursue these treatments.

Editor’s Note: The ACFA offers “The Family Manual,” a guide for people who live with someone with chronic pain. Readers may find this useful, and can order it on our web site (www.theacpa.org) or by calling our office at 1-800-533-3231.

I t began with two people who had known each other for more than 15 years living in two different states watching a tragedy in Louisiana called Katrina. Soon Robin Earp, Texas Regional Director, ACFA, and Chris Thomas of the American Legion Auxiliary in North Carolina developed an idea and a dream.

They organized a shipment of 167 cases of supplies to The Community Storehouse, in Keller, Texas. Chris Thomas led the effort to collect donations of gently used clothes, quilts and blankets, new clothes, and shoes for women, along with two handmade robes. Twenty-two cases contained cosmetics, toiletries, books, snacks, baby items, and toys, each designated for a male or female child, adult, or teenager.

These donations were collected by volunteers who also raised money, obtained the items at discount and packed the cases, even securing a donated driver to get the truck to Texas. There, Robin Earp was networking, trying to get these donations to the individuals who were flooding into Texas looking for shelter. She knew they would be in need for a long time, so even when the delivery was scheduled for Oct. 31, 2005, she was eagerly awaiting the truck’s arrival.

The project was a shared venture to rebuild lives and strengthen families and individuals by providing assistance and education during their time of need and crisis. Among the organizations that helped are the National ACFA in California, the Texas chapter of the ACFA, Villages of Woodland Springs Foundation, The American Legion Auxiliary, Reeds Unit 462, North Carolina, and the Community Storehouse, Keller, Texas.

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I would like to add some alternatives to your discussion on exercise in the Summer issue. Having the chronic pain condition RSD (Reflex Sympathetic Dystrophy) has taught me that while I must limit myself to what my body is capable of, I can still participate in different forms of exercise.

When my pain allows me, I want to increase my levels of activity. A restorative yoga class encourages my body and mind to relax. Yoga emphasizes breathing techniques, which help me focus on releasing the tight stiff fascia (like a tight rubber band waiting to break). I never worry about what others are doing around me; I listen to my body and modify the Yoga positions as needed.

Water therapy is another great way to unwind without stressing the muscles. It’s soothing and relaxing. There are many great stretches and strengthening movements you can do in the water. I find warm water more comfortable, because RSD does not respond well to cold but if cool water works for you, take the plunge.

Pilates is another type of movement exercise that can be done on the floor with a mat or on a specially designed machine. This will help to stretch, strengthen, and balance the core of the body.

The craniosacral system is a physiological system in which brain/spinal cord and central nervous system are all interconnected. Craniosacral therapy involves light soft touch that helps bring balance back to the body, a great way to release some of that taut connective tissue and relieve some of the spasms and stiffness.

Because RSD affects so many different bodily symptoms, I researched and learned about the Feldenkrais Method. This extremely passive movement exercise encourages movement through brain function and does not stress the muscles.

My therapists suggest trying Reiki, NRT, and NET, muscle testing and positive reinforcement through power of suggestion. Although nothing is a quick fix, over time and with dedication, I have experienced tremendous benefits from some of these therapies.

We need to become knowledgeable about our bodies and then we can begin to understand the influence that alternative activities can offer us. Those of us with chronic pain are on a challenging course. So don’t give up the marathon, just start to train differently for it.

Wishing you wellness,
Tracy Zuckerman