



CHRONICLE



When Family and Friends Share the Pain

by Penney Cowan, Executive Director, ACPA

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At the ACPA we know that chronic pain affects not only the person who is in pain, but also the entire family unit. When one member of the family is in pain and unable to assume his or her responsibilities, daily occurrences escalate into major problems. Financial commitments are difficult to meet when two incomes are reduced to one. Increased medical bills place heavier burdens on the family budget.

When pain becomes a member of the family, emotions become entangled in miscommunication, resentments, and confusion. Uncertainty about the future increases stress far above manageable levels. Life is more difficult with each passing day.

When one person in the family unit is “ill,” the responsibilities of daily life are left to the rest of the family. Attentions are focused on the person in pain and children may feel neglected. Where do the other family members go for help with all the problems that chronic pain creates?

We are a society of quick fixes and fast-paced lifestyles. When something is not working right, we expect it to be repaired immediately or replaced. We never give much thought to what would happen if we couldn’t fix or replace it.

Chronic pain is something that cannot be fixed or replaced. Instead it must be managed. The ACPA is dedicated to helping the individual with pain make the transition from patient to person

through peer support and proven coping skills. The person with pain must become actively involved in recovery. But it takes more than one person’s efforts. To regain control of lifestyles and restore appropriate functioning



within the family unit, everyone in the family must contribute. The family can work together as a unit to regain control of life.

By pacing yourself and managing your pain, you can continue to take part in activities with friends and family. While you may need to limit your participation and manage their expectations, it doesn’t mean that you must live in social isolation. A proper balance can be found. Many people find that their loved ones—and new friends in their support groups—are key to maintaining a healthy attitude and staying motivated to face another day.

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Staying Positive Helps Relationships Thrive

by Sally Price

Penny Rickhoff, an ACPA facilitator in Scottsdale, Arizona, knows how chronic pain affects relationships. It's her belief that she lost a husband and several friends, including a best friend, due to her chronic pain.

But the last thing she wants is pity. Penny believes that everything always turns out well for her, with the ACPA playing a large part in her good fortune.

At the time of her divorce 14 years ago, Penny was suffering from failed back syndrome due to the effects of osteoarthritis, degenerative disc disease, a couple of accidents, facet joint syndrome, and infection in a disc space after surgery. Added to constant back pain were spasms in her eyelids and a burning pain in her eyes caused by Guillain-Barré syndrome. At times, she said, it felt like someone had stabbed her in the eye.

Her husband was a real estate developer. The stress of his job, added to her back pain and eye problems, made for a volatile situation. "I got really depressed. I thought I should do something for myself," said Penny. "I went to the Mayo Clinic, was put on medications for eye pain, sent to a psychiatrist, and ended up in a divorce."

But Penny has a knack for looking for the good side of any situation, and saw benefits in ending some of the negative aspects of her married life. "I had to give up a nursing career to follow him around the country. Now I could find out who I was," she said.



Different Needs Complicate Relationships

She has also experienced the loss of friends due to her pain, she said. "My best friend just decided after 15 years that she didn't want to be friends with me anymore. I had always tried to be up for her, but she didn't want to put up with my situation. She was working and was healthy. I can't work. All I could talk about was my achievements before chronic pain."

Penny couldn't go to movies, take day trips, or attend dances where she might meet single people. "The few single friends I had don't call me anymore because I can't do things [they like to do]," she said.

But again Penny's belief that "life turns out for the good somehow" rang true. The ACPA group she has facilitated for 13 years introduced her to new people who have become wonderful friends.

"One is my best friend now. It's like when one door closes, another opens. Good things always happen to me eventually," she said.

Penny is currently finding out how good her new friends are. She was diagnosed earlier this year with small fiber neuropathy, which causes her feet to feel "like they're on fire all the time." Penny has been unable to walk much, and for awhile she couldn't drive. She found her support group friends to be most understanding. They would pick up prescriptions and groceries for her, and would visit her to play Scrabble or simply to cheer her up. "So out of all this I've really developed some closer friendships," she said.

Be Truthful to Manage Expectations

Dating relationships can be especially challenging when chronic pain is involved. When she was dating, Penny didn't encounter particular problems, except for the guy who was impatient when she was slow going up steps. As she recalled, he asked, "Do you want me to carry you up?"

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The ones who are true...will be by your side.

I have to share with them what I am feeling.

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Other than that instance, she found most men she dated to be understanding, probably because she always made her situation clear. “I explain in the beginning that I have limitations, and say, ‘I’d like to be friends with you but you have to understand there are times when I’m not dependable because of chronic pain.’”

“Most of the time it would work out fine,” said Penny. “I’m a very truthful person. They would usually say, ‘That’s okay. That may happen to me’ or ‘I may have to cancel because something comes up at work.’”

A high level of truthfulness helps manage expectations in dating and other relationships. So does picking friends carefully, according to Penny. “I select people who don’t care that I can’t hike mountains or play tennis anymore,” she said.

Penny has a surefire way to make and keep friends too. She is always trying new things, “so I’ll have something to talk about,” she said. People like interesting people, and Penny has traveled to over 50 countries, has her pilot’s license, has been a nurse and substitute teacher, studied interior design, and is now writing books. She just finished a children’s book she’s hoping to publish and plans to write a book about chronic pain.

This book will deal with the problems people with pain have, many which she has witnessed as regional director for the ACPA for 10 years.

But the best advice for dealing with relationships when you have chronic pain, Penny said, is to have a positive attitude. “Act happy and positive about things. You can choose how you act about your pain around people.”

Pain Can Change Attitudes

Samantha Nagy, 27, ACPA regional director in Michigan, incurred chronic pain after a tree fell on her in early 2003, and now has fibromyalgia, low back problems of degenerative disc disease and herniated disc, and severe migraines. She found out the hard way how she should act around people.

“The way you handle the relationships in your life totally changes when you have chronic pain,” she said. “For the first four years I handled my emotions and relationships completely wrong. I took out my frustrations and anger on the ones I loved, the ones who were the closest to me.

“I had a wall built up, shielding myself from any more harm. That was not the way to go about coping. I need the love, support, and guidance from my family and friends. I was fortunate that my loved ones were able to see

that I was having a hard time dealing with my pain and stuck by my side. They didn’t turn away from me.”

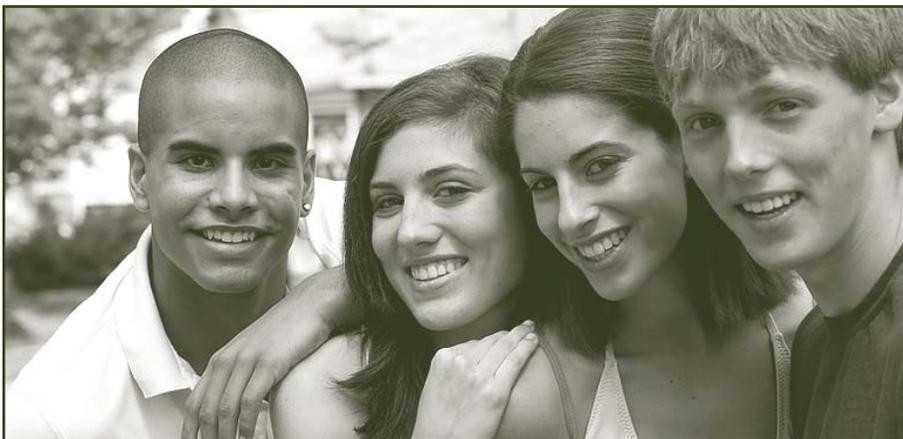
“My dad, boyfriend, and brother have been my rocks. I look back and realize how much I pushed them away and how bad I was to them. I’m so grateful that they were so patient with me and had so much faith in me. They knew that eventually I would come to terms with my conditions and learn acceptance.”

Learning to Accept the Situation

Samantha said that acceptance and communication are the keys to healthy relationships when you have chronic pain. She added, “The most important thing that I learned is that I had to accept my pain and my situation. That was the starting point. After that, I was able to interact with my loved ones better. I was able to embrace their love and support. Once I learned acceptance, my relationships began to change for the better.”

“I am no longer taking my aggression out on them. Instead, I talk with them, person-to-person, about what is bothering me. I talk to them about my pain and about my conditions. The only way my loved ones are able to understand what I am going through (or how I am feeling) is if I help them to understand. I have to share with them what I am feeling and why I am feeling this way.”

It wasn’t always easy. Some people that Samantha knew were “not up for dealing with a friend who has chronic pain, so they bailed,” she said. “But the ones who are true, the ones who love you the most, will be by your side till the end.”



Better Understanding Leads to Better Care

by Robert N. Jamison, Ph.D.

Individuals with chronic medical problems face a complicated and sometimes overly bureaucratic medical system. Today's doctors tend to specialize in particular areas of medicine and as a person with chronic pain you may see a variety of specialists and healthcare professionals. Each of these individuals may have a different slant on your diagnosis and make a different recommendation for treatment. After being seen by many specialists you may feel confused about who is responsible for your care. In addition, your dealings with employers, insurance carriers, and lawyers may cause you to feel trapped by a system that is time-consuming, complex, and frustrating.

Your doctor may be under pressure to see more patients as efficiently as possible. This works against your desire to have a one-to-one relationship with your doctor, to be regularly informed of your diagnosis and treatment, and to participate in an active way in your own care.

For you to get the best service from the medical system, you need to speak up for yourself, gather information about possible treatments, and ask questions. Ideally you should try to participate in all decisions about your care.

Unfortunately each pain center, treatment program, and hospital has its own way of operating. Some clinics may be more welcoming of your input than others. Nevertheless, it is important that each person with pain understand the training and background of his or her provider. You should be able to identify biases among healthcare professionals on topics such as chronic opioid therapy, workers' compensation, second opinions, alternative medicine treatments, and the value of invasive procedures and behavioral techniques.



To help you improve your relationship with your health care providers, the following points are worth considering.

1. Learn which doctors are best for you. Some physicians and healthcare providers who genuinely want to help you may not be able to do so because their training and expertise aren't relevant to your pain problem. These providers may not be up on the latest treatments and scientific literature and they may have trouble telling you that they don't know what to do. You should talk to other persons with pain to find out which doctors have been helpful to them. Try to figure out early on whether the doctor you are seeing can truly be helpful. Wasting months with a doctor who cannot help you will lead to more frustration and pain.

2. Strive to be understood. Chronic pain is a confusing condition to have, and it is also confusing to treat. Some doctors may have trouble totally understanding what is causing your pain.

Be consistent, honest, and clear in communicating with your doctor, and try not to be defensive if you aren't immediately understood. Don't hesitate to stand up for yourself as firmly and calmly as you can if you feel you aren't being heard.

3. Build Trust. Once you have found the doctor you feel can be most helpful to you, do all you can to get to know him or her and to build trust. He or she needs to know that you have good judgment and a strong sense of responsibility, particularly if the doctor is prescribing medication that can be abused. Being calm, straightforward, and friendly will help.

4. Do your homework. There are many useful websites devoted to describing treatments for pain—including www.theacpa.org. The more that you, as a healthcare consumer, know about options for treatment and the potential risks and benefits that each treatment can offer, the better you can make informed decisions.

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Get to know your doctor and build trust.

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5. Make the best use of your doctor's time. Doctors are under constant time pressure and appreciate you coming prepared for your appointment. Write down your questions in advance and bring along any information you have that may help your doctor understand your problem. Avoid turning your chronic pain into an emergency; that is, don't always wait until you are in a crisis to phone your doctor with urgent demands for immediate attention.

6. Get to know the people involved in your treatment. If the receptionists, office managers, nurses, physician assistants, and doctors involved get to know you as a pleasant, reasonable person, you will stand a better chance of getting prompt help when you really need it.

7. Work within the system. Find out from employees and other patients how your doctor's office or clinic is set up and then follow the standard procedures. If you don't, you may create problems and end up not getting the best treatment, even if you have the best intentions. For instance, some clinics require two days' notice for refilling prescriptions. Knowing this ahead of time will save aggravation later.

8. Use your pain management tools. By using pain management techniques such as pacing, problem-solving, and relaxation, you can improve your ability to cope with pain. When you have greater control of your pain, you will find it easier to work with your doctors and they will find you easier to treat.

Although we live in a society that offers the most advanced medical services in the world, the treatment of chronic pain is not an exact science. Much depends on your understanding of the problem, your active participation in dealing with it, and your relationships with healthcare professionals. By becoming knowledgeable, you can get the most from the medical system.

Dr. Robert Jamison is a Clinical Psychologist and Associate Professor of Anesthesia and Psychiatry at Brigham and Women's Hospital, Harvard Medical School, Boston. Excerpts in this article are from his book "Learning to Master Your Chronic Pain," 1996.

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Share the Pain CONTINUED FROM PAGE 1...

Helping Loved Ones Understand

There is no way for another person to feel your pain. As the articles in this issue of *The Chronicle* discuss, it is more important for friends and family to understand what their role is in helping you manage the pain. The [*ACPA Family Manual*](#) is an excellent resource for family members. It can help them realize that, while family members don't feel the physical pain, their lives are affected in similar ways. In this book they'll hear from other people who live with a person with pain and learn how to cope with the changes pain brings.

Many books that discuss how intimacy and relationships are affected by pain are listed in the [resources section](#) of the ACPA web site. Here are two new books on this topic.

Chronic Pain and the Family: A New Guide (The Harvard University Press Family Health Guides) Julie K. Silver, M.D. 176 pages, Harvard University Press (October 25, 2004) www.amazon.com

Chronic Pain and Family: A Clinical Perspective by Ranjan Roy www.amazon.com

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Improve Communication with Health Care Providers

by Layne Goble, Ph.D.

Anyone experiencing chronic pain might find himself struggling through multiple medications, treatments, and even multiple doctors in his effort to find some type of lasting relief. Unfortunately, this journey can involve some perils. Feelings of disappointment, anxiety, frustration, and despair are not uncommon and may even influence the way you interact with others—including your doctors. The relationship between you and your doctors is fundamental to developing an effective treatment plan for managing your pain.

Effective Communication

One of the most common concerns is, “My doctor doesn’t listen to me.” This breakdown in communication appears to happen despite the fact that you and your doctor are working toward the same goal. Although it’s easy to just say, “Everyone has bad days,” there are other forces to consider. Most doctors are now part of a larger system that requires them to see more patients in less time—causing them to be more direct during visits. You may feel anxious or have difficulty expressing yourself during a doctor’s visit. If you feel a visit is being rushed, it may be hard to know just what to bring up and what to leave unaddressed.

The ACPA website (www.theacpa.org) has several resources to help you better communicate with your doctor and make the most of the time you spend at your next doctor’s visit. These include:

* *The Live Better with Pain Log*, which allows you to record the severity of your pain on a numerical scale and address several key lifestyle factors related to pain.

* *The Quality of Life Scale*, which looks at pain not as an abstract number but as a factor that has an impact on your life.

These and similar resources can help you to communicate crucial information in a brief amount of time and may prompt your doctor to inquire further about issues important to you.

You may even consider sending this information in advance, so your doctor will be better prepared for your visit, which in turn, increases your chances of getting the best care possible.

Take an Active Role

Being actively involved in your treatment is the single most important factor for effectively managing your

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A multidisciplinary approach to pain management could include a physician, nurse, physical therapist, occupational therapist, psychologist, pharmacist, chiropractor, substance abuse counselor, and a vocational rehabilitation counselor in the same setting.

Information to Share with Your Doctor

- * Sites where you experience pain—including areas where the pain travels.
- * The severity of your pain—usually on a scale of 0 to 10 (where 0 = no pain and 10 = the worst pain imaginable).
- * Fluctuations in your pain.
- * Factors that cause your pain to increase.
- * Factors that cause your pain to decrease.
- * Usefulness of medications and other therapies.
- * Changes in your health and health behaviors that affect your pain.
- * Changes in your level of functioning and the onset of any disability.
- * Emotional factors related to your pain.

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pain. Your doctor is more likely to be engaged in your treatment when you are actively engaged in following his or her recommendations.

Your doctor may have mentioned the benefits of increasing your physical activity, quitting smoking, developing better sleep habits, managing your weight and stress, or giving up caffeine. There's little doubt that making any one of these changes may seem difficult for many people—especially for anyone experiencing chronic pain. However, discussing these challenges with your doctor shows your willingness to take an active role in your treatment and allows him or her to consider a wider range of treatment options.

There are also times when not following medical advice may have more serious consequences. Doctors often become very concerned when a patient abruptly discontinues a medication or treatment without consulting them. Finding effective pain management interventions frequently involves several trials of medications and non-pharmacological treatments before finding one that is effective without unacceptable side effects. You should speak with your doctor about the benefits and risks of any treatment, and have a clear plan in place for immediately communicating unexpected side effects. Tell your doctor right away, rather than waiting for your next appointment—which could be months away. The [ACPA CARE Card](#) helps provide useful information for taking your medications.

Keep in mind that overusing your medications, taking medications that are not prescribed to you, using illegal drugs, or excessive alcohol use will often lead to immediate restrictions on the medication options available to you. This is especially relevant when

opioids are involved. Misuse of medications, drugs, or alcohol can interact with prescribed medications in ways that could severely compromise your health and may even have the potential to be deadly. Furthermore, your doctor's license could be put in jeopardy if he or she were to continue to prescribe medications knowing that you're misusing medications or taking illegal drugs. If you or others are concerned about your use of alcohol or other substances you should speak to your doctor about treatment options.

A Multidisciplinary Approach

A multidisciplinary approach to pain management could include a physician, nurse, physical therapist, occupational therapist, psychologist, pharmacist, chiropractor, substance abuse counselor, and a vocational rehabilitation counselor in the same setting. They usually address the biological, psychological, and social aspects of your pain experience in an effort to help you increase your level of activity and functioning. While you may have already tried one or more of the medical interventions included in the multidisciplinary approach, the coordination of therapies is often more effective in managing your pain than trying each alone.

Within a multidisciplinary pain management program, if you find interventions that are unfamiliar or upsetting, discuss the benefits and risks

with your doctor. It's to your advantage to keep an open mind about these treatments as you weigh your options. Vocational rehabilitation may be difficult for anyone who has been on disability for extended periods. Physical therapy may be intimidating for anyone fearing a painful flare-up. Changes in medication may be daunting for anyone already comfortable with their course of therapy. Working with a multidisciplinary team can provide the structure and support to expand your options for successful pain management.

Psychologists and other mental health professionals may take a holistic approach that considers biological causes of your pain. They also recognize that chronic pain can also lead to stress in your life and in your relationships with others. They often provide brief interventions to help you better manage your pain, improve your mood, and address interpersonal issues related to your pain experience. They also address depression, anxiety, or anger. Remember, the better you feel emotionally, the better you will be at managing your pain.

Layne A. Goble, PhD, is a postdoctoral psychology resident with Clinical Health Psychology, VA Connecticut Healthcare System, West Haven, Connecticut.

How Parents Feel When their Children are in Pain

by Maggie Chesnut, National Coordinator, ACPA Growing Pains support group

I spent the summer living and teaching in Cusco, Peru. My host, Malu, lived with her two children in a middle-class home in the center of the city. When I first arrived Malu apologized that I had to make my own bed; she was sure that my servants did it for me in the United States. Neither Malu nor I had accurate ideas of what life was like in the other's country.

Everything in Peru seemed very different to me. Houses were concrete instead of wood or brick, Malu's sister and her mother lived on the floors above and below her, and lunch was the heaviest meal of the day. The taxis raced around with no speed limits or seatbelt laws and markets of vendors behind card tables replaced grocery stores. But, when Malu quietly described the pain and frustration she felt as a mother of a chronically ill child, when her eyes dropped to her clasped hands and she sighed, I saw clearly how human emotion and compassion could transcend distance and cultural differences.

Malu's 16-year-old daughter Joanna suffered from rheumatoid arthritis (RA), limping around the house and crying at night with pain. It was clear that Joanna's physical pain was reflected in Malu's tears. She felt responsible for Joanna's pain and blamed herself every time Joanna's leg began to hurt. As Malu looked into my eyes and pleaded for an answer, I remembered my own mother and father, upset and frustrated every time I had a celiac attack.

"But is there a cure?" she kept asking. I tried to explain that a chronic autoimmune disease would never go away, but that did not mean that her daughter's life was ruined. To Malu, finding a job, having children, and general happiness appeared impossible for a daughter with incurable pain.



She worried about Joanna finding a husband in a country where the main topic of conversation seemed to be, "Do you have a boyfriend?"

Suffering is not limited to the person with chronic pain or illness; it affects all those who love her. It was almost unbearable for Malu to accept that her daughter might have to live with such pain. She was just as upset as Joanna, if not more, every time a doctor's prescription did not "cure" the pain, as she still hoped it would.

In addition, Malu, a single mother, bore the cost of searching for relief on her own. When Joanna begged for money to go clubbing or traveling, her mother had to disappoint her, knowing there was no money to spare. Her feelings of failure as a parent were clear. Malu felt that it was her duty to protect and provide for her children, but she could not defend Joanna from the pain.

In broken Spanish I tried to explain that pain was not death, and that Joanna could live a full and happy life despite chronic pain. I wanted Malu to know that it was not her fault. Even though there was no cure, Joanna could learn to accept her pain. If she could educate herself about her symptoms and treatment options, she could manage her pain, and gain control of her life. Malu was not entirely convinced, but she understood me.

During my time in Cusco I helped Malu and Joanna find websites and books that furthered their understanding of RA. Although at first I was intimidated by the cultural differences, in the end it was not where we lived or our language that mattered, but the experiences themselves—even the painful ones—that brought us together.

Growing Pains is a support group for chronically ill youth. For more information, contact Maggie Chesnut, Growing Pains, P.O. Box 346, Putnam Valley, NY 10579 or GrowingPainsACPA@aol.com.

Recent Advances in Pain Treatment

by Steven Feinberg, MD

So what's new in pain treatment?

Some of these relatively new and interesting developments in pain treatment represent possible successes, while others provide new information about possible problems or side effects. It is important to remember that new developments have not withstood the "test of time," during which more revealing research may be conducted. Nevertheless, it could be important for people with chronic pain to consider these new developments as they make treatment decisions.

Medications for Pain

Duloxetine (Cymbalta) for neuropathic pain

The antidepressant duloxetine has demonstrated benefits for people with some forms of neuropathic pain. It is FDA approved for painful diabetic neuropathy and it has shown efficacy in fibromyalgia but is not FDA approved for it. Research has not been published on the effectiveness of duloxetine for other types of neuropathic pain, musculoskeletal (i.e. arthritis), or visceral pain, like interstitial cystitis. It is important to note that although duloxetine and related drugs are referred to as antidepressants, recent evidence does suggest that it may have direct analgesic effects beyond its antidepressant benefits.

Pregabalin (Lyrica) for managing fibromyalgia

On June 21, 2007, the anti-seizure drug pregabalin (Lyrica) was approved by the FDA for the management of fibromyalgia syndrome. The agent is also approved for the management of neuropathic pain associated with diabetic peripheral neuropathy and postherpetic neuralgia, and in epilepsy for the adjunctive treatment of partial onset seizures in adults. Pregabalin not only appears to improve pain in persons with fibromyalgia, but it also has a broader effect on improving function, according to a randomized, placebo-controlled trial (abstract 695) presented at the 2007 annual meeting of the American Pain Society. Recent studies show pregabalin efficacious for central pain (brain or spinal cord injuries) and pain after surgery.

Possible new risks with chronic use of PPIs

Many people with pain take non-steroidal antiinflammatory agents (NSAIDs). Because of heartburn, ulcers, and other gastrointestinal problems, their doctors also prescribe the use of acid-suppressing proton pump inhibitors (PPIs) for prevention and treatment. A study published in 2006 raised concerns because the chronic use of PPIs might have a significant impact on the rate of hip fractures. The authors think that acid-suppressive therapy may be increasing the risk of hip fracture by decreasing calcium absorption. Thus, as with all medications, PPIs must be used with caution and the disadvantages must be weighed against the benefits.

Possible Treatments for CRPS

It has been suggested that N-methyl-D-aspartate (NMDA) receptors may play a role in clinical chronic neuropathic pain, including complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy (RSD). If this is true, then it is possible that blocking NMDA receptors would be beneficial. But these agents' side effects include lightheadedness, dizziness, tiredness, headache, nervous floating sensation, bad dreams, and sensory changes. Drugs that have clinically relevant NMDA-blocking properties include ketamine, amantadine, memantine, dextromethorphan, and methadone. The concept of NMDA blocking in neuropathic pain is reasonable but there is a strong need for more research and perhaps development of newer agents with fewer central nervous system side effects.

Recently, there has been significant interest in the use of thalidomide as a treatment for CRPS. This is based on the possible role played by natural chemicals found in the body called inflammatory cytokines, which thalidomide inhibits. There are no published clinical trials on thalidomide use in CRPS, only case reports demonstrating benefit. The drug is currently being studied in clinical trials, but because of its history of causing birth defects, women of childbearing age have been excluded, and extensive monitoring is required.

Bisphosphonates (e.g., pamidronate, clodronate, and alendronate) inhibit calcium bone resorption and have demonstrated some benefit in CRPS studies. Further research is needed. The data on bisphosphonates looks promising but side effects are a major concern.

Topical DMSO (dimethyl sulfoxide) 50% and oral NAC (N-acetylcysteine) recently were shown to possibly have some benefit in CRPS but there is no scientific evidence yet.

Concerns about Long-term Use of Opioid Analgesics

While opioid (narcotic) analgesics have been the mainstay for treating chronic intractable pain for quite some time, there are growing concerns about the long-term use of high dose opioids.

The problem with long-term reliance on opioids is that prolonged use may heighten the risk of accidental death from respiratory depression (although most people do become tolerant to the respiratory depressive effects). It can also result in problems including tolerance, hyperalgesia (abnormal pain sensitivity), hormonal effects (decreased testosterone levels, decreased sex drive, and irregular menses), depression, and

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ACPA Update

New ACPA Groups

Welcome to our new groups and facilitators.

Jana Hamik

Santa Rose/Sebastopol, CA

Jeanne Telep

Fort Myers, FL

Sherry & Cliff Mulder

Grand Rapids, MI

Jerry Becker

Bronxville, NY

Beth Fellows

Asheville, NC

Rex Marshall

Uniontown, OH

Elizabeth Blaney

Medford, OR

Elisha Paolini

Telford, PA

Tom Tisher

Green Bay, WI

Marie Berrios

Puerto Rico

New Regional Directors

Samantha Nagy

Michigan

Michael Scott

Washington



IMMPACT Study Reveals Common Concerns

When it comes to persistent and recurring pain, no matter what the cause or lifestyle might be, most people talk about the same issues. While this may make people with pain seem similar, there is still a need for each individual to have a tailored approach to pain management.

This complex problem was recently explored in “Identifying Important Outcome Domains for Chronic Pain Clinical Trials: An IMMPACT Survey of People with Pain,” in-press and scheduled for publication in *Pain*, The Journal of the International Association for the Study of Pain.

The Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) was formed in 2002 to recommend a set of outcome domains and measures for chronic pain studies. These recommendations were based primarily on the perspectives of clinicians and researchers. This new study, however, was done to learn what individuals with chronic pain consider most important.

In the study’s first phase, focus groups of patients were asked to identify 19 aspects of their lives that were significantly affected by the presence of their pain symptoms. They were also asked what criteria they would use to evaluate whether or not treatment was effective in alleviating these problems. In phase two, through a survey posted on the ACPA website, 959 participants were asked to rank the importance of various quality-of-life aspects on a scale of one to ten.

The results indicated that all 19 aspects of daily life mentioned by the focus groups were considered important (score of 8 or greater) by the survey participants. In addition to pain reduction, these most important aspects were enjoyment of life, emotional well-being, and reducing fatigue, weakness, and sleep-related problems.

The study showed that chronic pain clearly affects health-related quality of life and that people with pain consider functioning and well-being as important parts of their lives that are affected by their symptoms.

When asked what participants would like most from new treatments, focus group participants answered: getting restful sleep; having more energy; be able to clean my house, and be able to take a 2-hour trip. One said, “Just 2 hours of anything and I could go for sure, and just pick up and take off without thinking that I’m going to pay for this tomorrow.” Another wanted to have better control and stop taking so many pills.

Pain had an impact on 19 important aspects of daily life including sleep, sex life, employment, home care, relationships, family life, social and recreational activities, physical activities, emotional well-being, fatigue, weakness, and cognitive functioning. Survey respondents said that pain very significantly interfered with general activities, mood, walking ability, work/housework, social/recreational activities, relations/friendships, sleep, and enjoyment of life.

The study authors said that knowledge of the pain-related outcomes that people with pain consider important has the potential to greatly improve assessments. Does the impact of a pain treatment include beneficial effects on patient well-being and health-related quality of life? This research can help improve the validity of comparisons of the overall benefits of treatment.

Identifying Important Outcome Domains for Chronic Pain Clinical Trials: An IMMPACT Survey of People with Pain. Dennis C. Turk, University of Washington; Robert H. Dworkin, University of Rochester; Dennis Revicki and Gale Harding, United BioSource Corporation; Laurie B. Burke, Sharon Hertz, and Bob A. Rappaport, United States Food and Drug Administration; David Cella, Northwestern University; Charles S. Cleeland, MD Anderson Cancer Center; Penney Cowan, American Chronic Pain Association;

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John T. Farrar, University of Pennsylvania; and Mitchell B. Max, National Institute of Dental and Craniofacial Research, National Institutes of Health, Department of Health and Human Services.

Sharing the Consumers' Viewpoint

When Penney Cowan, Founder and Executive Director of the ACPA, addressed the American Bar Association Section of International Law, she told them that information about health care must be provided at a level that the majority of consumers can understand. She presented "Regulating the Reimbursement of Medicine: Rights of Patients and other Stakeholders from a Consumer's Point of View" at the group's fall meeting in London, England, October 3-6, 2007.

"There is a wealth of information from a variety of sources, but we struggle to unlock the information, which is hidden in unfamiliar language and massive forms," she said. "Do we really have a choice of physicians, treatments, tests and medications? Or do we find

ourselves in a maze of regulations and dead ends, controlled by third party payers, that tend to worsen our suffering and, in many cases, prevent us from receiving proper or timely medical care?"

Penney explained that obstacles stand in the way of true Evidence Based Medicine, which should be a blend of science, clinical practice, and consumer values to inform healthcare delivery and decision making. Along with researchers, payers, academics, and policymakers, consumers must have a voice in decisions about access, regulations, care decisions, and implementation of services.

"If we, as a society, do not begin to implement these recommendations, we put ourselves at risk for less choice, less involvement in treatment decisions, and less access to potentially life-enhancing therapies and interventions," said Penney. "It is imperative that the consumer have a voice at the table every step of the way." | TOP |

Recent Advances CONTINUED FROM PAGE 9...

suppression of the immune system. While opioids may initially be prescribed to reduce pain and we hope improve function, the treatment may actually produce the opposite result.

The exact relationship between higher opioid dosage and risk is not yet clear, but a troubling pattern of increased numbers of deaths associated with prescription opioid use has emerged during the same period that average dose size has significantly increased.

Respiratory depression (a reduced drive to breathe) with opioid use is a serious concern. It can be fatal when doses are increased rapidly or in opioid naïve persons. In addition, opioids become particularly dangerous when used in conjunction with alcohol or with other medications that can worsen respiratory depression—sedative-hypnotics, benzodiazepines, anti-depressants, and muscle relaxants—or with alcohol.

Part Two of this article—implantation technology and other treatments—will appear in the next issue of The Chronicle.

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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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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Board Member Profile: Nicole Kelly

by Alison J. Conte

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

Nicole Kelly and the ACPA go way back.

In fact, she was the organization's third board member, joining almost 25 years ago in 1983, just three years after ACPA was founded.

She was recommended as a board member who could provide expertise in writing and public relations, two skills strongly needed by the fledgling ACPA. "With Penney [Cowan], I worked on all the manuals, marketing materials, and the newsletters," Nicole said. "We were lucky to have a good mix of skills in our board members—medical, legal, and financial expertise—that allowed us to do the work ourselves."

A human resources communications consultant living in Pittsburgh, Nicole contributed countless hours of time to ACPA, serving as president twice. Currently, she oversees production of

the website and *The Chronicle*, coordinates the ACPA annual board meeting, and directs many marketing efforts. Since she retired from formal employment several years ago, she is now a grandmother and full-time volunteer. Nicole was again elected ACPA board president in October 2007.

"It has been very satisfying for me to see this organization grow and reach the large audience we reach today," she said. "I think I'm a good problem solver and writer. It's been rewarding to find a way to use my skills to make a difference in people's lives."

Nicole is pleased that ACPA has stayed clearly focused on its mission, always asking what any new project would mean to a person with pain. "This has kept us fresh and tightly directed. This perspective and the expertise that grows from it have made us a valued voice in the international discussion about pain, treatments, and policy," she said.

Looking ahead, Nicole envisions a future in which ACPA goes beyond paper manuals to share knowledge

through interactive, online communications. "We will also try to meet the needs of special interest groups—adolescents, people in rural areas, the urban poor, and other underserved and overlooked populations," she said.

One current project, the study on pain in the emergency department, addresses yet another often-missed element of access to care. "There is a need for greater understanding on both sides of the Emergency Department door—among health care providers and people with pain," said Nicole.

All this requires a broader financial base, to support staff and new electronic initiatives. "While we are thrilled to have support from pharmaceutical firms, we must go further and diversify our funding sources," she said.

"With such a small staff, the ACPA has been challenged to mobilize and engage the board members in ways that move our agenda forwards," said Nicole. "We have the talent and the interest. We need to transform that interest into action." | TOP |

Pain Relief: Your Way

Have you developed a special approach to pain management? Do you use a hobby, unusual volunteer work, personalized meditation technique, or homemade assistive devices to help you cope?

We would like to hear about it for a story in *The Chronicle*. Please describe it, and yourself, in a few paragraphs and we'll include you in the story. Write to Alison Conte, Editor, 112 Bower Drive, Sewickley PA 15143 or ACPA@pacbell.net before January 15.



Book Reviews

The Anatomy of Hope. How People Prevail in The Face of Illness

By Jerome Groopman, MD

Reviewed by Alison J. Conte

Dr. Jerome Groopman, a professor at the Harvard Medical School, scientifically examines the biology behind hope and how physical changes can make it easier to be hopeful. In turn, hopeful feelings can actually improve the physical condition.

“Hope can flourish only when you believe that what you do can make a difference, that your actions can bring a future different from the present,” Dr. Groopman says, adding that to have hope is to believe you can control your circumstances.

Dr. Groopman also discusses his early years as a physician, in which he struggled with telling seriously and terminally ill cancer patients their prospects. Would knowing their prognosis curtail false hope or would it result in less pleasure during their final days? He learned that his patients were more resilient than he thought, and that it was important to give them opportunities for hope.

Because he believed that hope could actually influence the possibility of a cure, he sought “a place where both hope and truth could reside.” He describes patients who reach back to the “touchstones of one’s heritage and faith to find freedom of the spirit and control over one’s life.”

He admires patients who continue to hope for a cure even when faced with cancer, pain, and difficult therapies, saying, “To hope under the most extreme circumstances is an act of defiance that ... permits a person to live his life on his own terms. It is

part of the human spirit to endure and give a miracle a chance to happen.”

He also learned the value of providing the “medicine of friendship,” often as important as any other treatment in healing the body and the spirit.

The author continued to explore the biological mechanisms by which the feeling of hope can contribute to clinical recovery. He now asserts that hope can change brain chemistry, reducing the pain we feel, improving muscle, cardiac, and respiratory function.

This book is very interesting to read, as Dr. Groopman discusses his theories through the stories of very ill patients, including himself. He reveals how their sense of hope, or lack thereof, influences the outcome of their illness. He easily explains complex medical cases and uses a story-telling style to involve the reader.

Random House Books, 272 pages, \$24.95, ISBN: 978-0-375-50638-3 (0-375-50638-1); www.randomhouse.com

The Myth of Pain

By Valerie Grey Hardcastle

Reviewed by Tracy Zuckerman

The Myth of Pain is an advanced condensed course on a wide variety of extremely intellectual concepts and theories. I hoped that in reading this book I would discover a new bit of information that could provide me with some insight about chronic pain. I feel that those of us who live with chronic pain must continually educate ourselves about treatments/theories and always advocate for better health.

Pain is a very diverse phenomenon and has many different interpretations for each of us as individuals. Our bodies perceive and receive sensations

of pain as warning signs to pay attention. So it was with anticipation that I tried to stay focused on the accumulation of knowledge and facts that were presented in the book.

The author states that “pain research has been unchanged for a century” despite it being a primary cause of disabilities and missing work. She says, “in short, pain is the most disabling disease around.”

We know there are many dimensions to pain but readers will be impressed with the variety of views and theories that exist. The author presented much data and research and explored these in detail. It would be helpful to have a medical dictionary nearby.

The author states many facts and opinions while maintaining that pain should not be considered a mental disorder, and discussing the DSM guidelines. At times, I felt the book would be too complex for the average person, as I had to digest and re-read many parts. But there were glimmers of positive things that were clearly stated. For example, she discusses how doctors could spend more time and money on different tests proving that sometimes they can then determine the complex origin of the pain.

I’m not sure if this book clearly addressed the needs of those with chronic pain. But it does cite theoretical knowledge and many different hypotheses. At times, it was a tedious struggle and very academic. I think doctors/therapists and philosophers should read this to understand the mind, body, and psychic connections to pain, but even as an educated person with pain, this book was a little over my head.

314 pages from *The MIT Press* (November 19, 1999); \$57.50; ISBN-10: 0262082837

Thank You!

At this time of year, we like to thank those who support the ACPA through membership. Anyone making a donation of \$25 or more receives a membership card, a subscription to *The Chronicle*, and a 10% discount on all ACPA materials. More importantly, your generosity—at any level—helps us continue to enhance our services for people with pain. With members' help we can continue to focus on the needs of the individual, working one-on-one to offer education, hope, and support to improve quality of life.

Donations also allow us to bring the consumer's point of view to key medical, legislative, and healthcare forums. Your contributions support our website, pain management tools, and materials and finance new initiatives to learn more about how to help people with pain.

As you join with your friends and family during the holidays, and look forward to 2008, please consider a tax-deductible donation to help us make a difference. You can donate through the website, www.theacpa.org/donate.asp.

Since 1980 the American Chronic Pain Association has provided people who must live with daily pain a means to help themselves to richer, fuller lives. We are grateful to have the support of these corporate sponsors for our mission:

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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.