



CHRONICLE



Driving with Four Flat Tires

by Penney Cowan, Executive Director, ACPA

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Looking for a simple solution to managing pain usually turns into an endless series of tests and treatments, always hoping to find the silver bullet that will eliminate the pain. Our expectation is that if we can find the right medication or the right treatment our pain will be gone and we can get on with our lives.

What we don't realize is that even with the most effective medication—the one that will provide us with as much relief as anything available—there will still be some level of pain, pain that we may have to live with.

The problem for so many of us is that pain becomes our identity.

As much as I fought it, during my journey to find a solution to my pain I lost who I was. I defined myself by my pain, more precisely, by the abilities that my pain allowed me to retain. I became so consumed with my pain that all of my energies were focused on the pain, how to rid my body of unrelenting pain, and getting back to life the way it was before the pain.

Like so many others, I looked for the quick fix, the magic that would instantly make my pain vanish. It made no sense to me that with all the modern miracles in medicine there was no way to relieve my pain. What I didn't realize then is how complex chronic pain is. I didn't know how many areas of my life—and my family's lives—the pain had invaded.

No Miracle Cure

In my six-year journey to find relief I did not realize just how much of myself I had relinquished to my pain. I finally learned that the fix could not be simple; it could not be as easy as taking a pill or discovering the "miracle" cure. No, the solution would take an approach that was completely foreign to me, as it would be to anyone who travels down this road. And traveling down a road might be the best analogy to explain the journey from disabled patient to functional person.



A person with pain is like a car with four flat tires. When we find the right medicine we can fill one of our tires. But we still have three flat tires and are unable to move forward. The solution requires far more than we anticipate. We must ask what else we need to fill our other three tires so that we can resume our life's journey.

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The Good and Bad of Pain Programs

by Sally Price

The pain program Lucy Wentworth* of Tucson, Arizona, attended didn't help her pain so much as it helped her change her attitude.

"I found out that I wasn't a fruitcake . . . that I wasn't just a complainer or whiner. There really was something to it," she said of her chronic headaches and the 18 days she spent at the Michigan Head and Pain Clinic in Ann Arbor. "I learned there are a lot of people out there dealing with pain as bad or worse," she said.

The 53-year-old ACPA co-facilitator has been dealing with headaches, often constant, since she was 10 years old. Though no single cause has been found, falls, stress, and muscle injury in her head and neck may have contributed. She feels pain all over her head, which is not a classic migraine pattern, and once went eight weeks with continuous headaches.

Sometimes the aggravating factor is the weather. As Lucy said, "It's monsoon season now in Arizona. The barometric pressure is going up and down, which has really increased my headaches."

Starting from Scratch

When she went to the pain clinic 15 years ago she first felt like she was in prison. "You get poked an awful lot. But it really is a good clinic—it has good doctors and nurses," she said. "They take you off all narcotics so they can start from scratch. They start trying different things (to find) what works with you."

One thing that worked for Lucy was intravenous DHE (Dihydroergotamine), available in hospital emergency rooms. The staff tried many other migraine preventives (abortives) to no avail.



"They made us exercise. They made sure we didn't eat certain cheeses, red wine, nitrites (in bacon and luncheon meats), and chocolate. They didn't let us stay up late; we had regular sleeping hours. We were taught how to manage stress. The relaxation tapes and biofeedback helped. We even tried different pillows," she said.

Education classes recommended against extreme aerobic exercise, as building up the heartbeat too quickly could kick off a migraine, Lucy explained. "Instead of walking fast, (we learned to) walk longer and slower." Men who had cluster headaches were often helped by oxygen treatments.

"The best thing about the program was the education and that it validated my pain," she said. But make sure your insurance covers it, Lucy advises others. She found out too late that her insurance would not pay the clinic's total \$20,000 cost.

Diet, Exercise, Massage, and Medication

Lucy said her headaches are now under control through a combination of therapies: reducing stress (by leaving

her job), low dosage opioids, massage therapy, exercising on a treadmill, and watching what she eats. She was recently diagnosed with diabetes. "Since I've been following a diabetic diet (low in carbohydrates, increased protein, vegetables and fresh fruit, and no refined sugar) my headaches have been better," she said. After a therapist massaged the trigger points between her shoulder blades, Lucy went several months with no headaches at all.

What is her advice about going to a good pain program? "I would really recommend it," said Lucy.

The Right Mindset Matters

Not all experiences with pain programs are good. But Darlene Cassaw, 57, of Dahlonga, Georgia, does not blame the program. "It didn't work well because I was very negative about it," said this former South Carolina ACPA facilitator.

Challenged with all-over muscle pain from multiple sclerosis since 1979, Darlene said she received 40 injections in her muscles during a six-week program in a Savannah, Georgia pain program in 1982. It also included

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Be grateful for what you have and don't focus on what you don't have.

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regular exercise and psychological counseling.

A 12-week program in Atlanta in 1990 was much more successful. "It was all about education, a positive attitude, and keeping physicians on the same page," she said.

"We learned yoga. Even back then it was really tough to accept that exercise would help the pain and that there were alternatives to drugs. It was about learning not to rely on a doctor to write a prescription," she said.

A typical day in the Atlanta program included swimming and other exercises, individual and group therapies, educational videos, and talks. Since it was located in a teaching hospital, there were frequent interviews by medical students. Participants also experienced withdrawal from pain medications.

Open to the Mind-Body Connection

Darlene learned why chronic pain happens and how to use the mind to ease it. "It helped to be open-minded enough to use natural therapies," she said, adding that the first time she tried yoga she could barely reach the floor.



Darlene said a good pain program needs to be very well-rounded with emphasis on exercise and "taking control of your own body." She said, "I used to be on 60-90 mg. of MS Contin™ three times a day. Now I take 15 mg. one time a day. That pretty much sustains me." She has continued practicing yoga and for the last 10 years has also been using an implanted pump to control pain and muscle spasms.

And of course, the right mindset is important. "You have to want to get better," she stressed. "I hear so many crying out, 'Pity me, pity me.' I will understand you, but I won't pity you."

If you're angry, she said, "Get angry enough at doctors that you want to take control." But don't stay angry, she cautioned. "If people are angry they can't get better. Anger causes stress. Stress causes muscle spasms. Spasms cause pain. It's a vicious cycle."

Darlene said she still has pain but is able to put it in the background. What is her best advice to other persons with pain? "Be grateful for what you have and don't focus on what you don't have," she said.

Education and Support

LeeMoile "Lee" Westerlin of Norwalk, California, was handling the pain of her multiple diagnosis. She didn't think she needed a pain program, but she admitted she was curious.

Today she is glad she joined the Kaiser Permanente's Pain Program, an award-winning program. She learned a lot from the classes, which included exercise and "constant feedback on what you could do to help yourself."



"I never had heard of endorphins (the body's natural pain-killers that are increased by exercise and laughter) before. I didn't know you have to get about four hours into sleep until your body starts healing. I hadn't really looked at pain and noted how it progresses," she said.

The ACPA offers support groups as part of the Kaiser after-care program in California. Now Lee uses ACPA's philosophies and policies in the Kaiser support group. "The ACPA has worked beautifully with the (Kaiser) facility. They lead you literally step by step. I'm really impressed with them," she said.

Since she was 13 years old with back problems, Lee has dealt with pain from multiple sources. She has spinal stenosis, Crohn's Disease, Lupus, pulmonary fibrosis, severe kidney disease, severe arthritis, GERD (reflux disease), and frequent bladder and urinary infections. "So if one isn't acting up another is," said Lee with a customary laugh.

Lee lives with her husband who is 85 and has Parkinson's disease. Her four children, eight grandchildren and three great-grandchildren all live close by. She keeps her positive outlook—important in any pain program. She said, "I've been blessed. At 78, I'm still going . . . and I have a marvelous family."

Whether a person with pain goes to an ACPA support group or a pain program, the important thing is getting out there, said Lee. "Realize your pain is insignificant to what others are going through. Get out in the public and try to help others."

* (not her real name)

ACPA Surveys Members About Pain Rehabilitation Programs

by Erin Kelly

Over ten weeks in late 2006, the American Chronic Pain Association (ACPA) conducted an informal online survey about members' experiences with multidisciplinary pain rehabilitation programs.

The 305 members who responded reported themselves to be people who had had intense pain for years. The survey uncovered a surprising number of doctor and emergency room visits. It showed that many people were successful in finding pain rehabilitation programs and receiving insurance coverage, but that the types of programs available varied widely. The survey also showed that most people benefited from their pain rehabilitation program experiences.

of \$12,000 or less. Another 25 percent had income of \$24,100 to \$50,000, but only 26 percent of respondents reported household income of more than \$50,000. About two-thirds of the respondents were female and nearly all participants were between 30 and 59 years old.

Experience of Pain

Survey participants had experienced pain for an average of 9.5 years. Most respondents reported having had pain for three to nine years, but 37 percent of respondents had experienced pain for more than 10 years. Chronic Fatigue Syndrome was reported by 35 percent.

Before entering a pain rehabilitation program, the vast majority of the survey population had intense pain. Sixty-nine

half, 41 percent, reported consulting three to five physicians and 17 percent had seen more than ten physicians. Also, more than half the group (55 percent) saw doctors frequently—once a month or more—before entering a pain rehabilitation program. They also used hospital emergency departments when pain went out of control: 64 percent had used emergency rooms, and 35 percent visited emergency departments four or more times a year before the pain rehabilitation program.

Access to Pain Rehabilitation Programs

Eighty-seven percent of the survey respondents had used a pain rehabilitation program and 34 percent had attended two or more. Nearly half of the people had entered pain rehabilitation programs within the past two years (2005-2006).

They reported mixed success at finding programs and getting insurance coverage. About half the respondents had difficulty finding a pain rehabilitation program, but half said they did not have much trouble.

Most of the people who found a program did get insurance coverage for it (104 people of 167 who answered this question). Ironically, some respondents reported that their worker's compensation program was helpful in finding and paying for the program, but other respondents reported that worker's compensation was unhelpful or would not pay for the program.

Wait time to enter the program was typically low; half the respondents were able to start their programs one week to one month after starting the process. One-quarter of the respondents reported waiting three months or more.



Respondent Profile

The majority of respondents were white and well educated—80 percent had attended college or technical school and 17 percent had done graduate-level work. However, their income levels did not correspond with education: 35 percent reported annual income

percent of respondents reported pain of 8, 9, or 10 on a scale from 1 to 10. Another 19 percent ranked their pain at a 7. Very few reported pain at level 6 or lower.

Almost all, 93 percent, of the survey group had seen three or more doctors to treat their pain symptoms. Less than

ACPA hopes to encourage more research into multidisciplinary pain rehabilitation programs and their outcomes.

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Structure of Program

The structures of pain rehabilitation programs varied widely. Seventy-five percent of respondents said they attended the program one to three days a week and for only one or two hours a day. However, 13 percent of respondents reported a more intense experience, attending their programs five to seven days a week and for more than four hours a day.

Only a quarter of the programs involved family members in the treatment. However, the overwhelming majority of those people who used this feature believed it was helpful.

Improvement After Rehabilitation

About half of the people found pain rehabilitation programs helpful. Fifty-four percent of respondents said their pain levels had improved after the program and 49 percent reported improvement in function.

Emergency room visits decreased after the program, although they were not eliminated. Only 30 percent of respondents who participated in a pain rehabilitation program had used an emergency department for pain treatment after the program, compared to 64 percent of all respondents. After the program, 78 percent of people reported four or fewer emergency room visits per year. Only 4 percent of rehabilitation program participants used the emergency department more than 15 times a year, compared to 10 percent of nonparticipants.

Regular physician visits remained about the same for program participants. Fifty-one percent reported seeing a doctor for pain between four and 15 times a year.

Use of opioid pain relievers did not seem to increase or decrease after participation in a program—but some fine-tuning seemed to have occurred. About 65 percent of respondents took opioids before participating in the program, and 65 percent were taking opioids at the time of the survey. However, 27 respondents reported that they stopped taking opioids after entering the program and 30 respondents said that they started taking opioids after entering the program. It's possible that being in the program helped people to realize whether or not the medication was a good choice for them.

Many survey respondents (65 percent) believed that opioids are helpful in pain management.

Unfortunately, a few people believed that the program caused them harm. Twenty-five survey respondents (10 percent of those who attended a program) believed the treatment caused additional physical symptoms or emotional harm. In some cases, respondents felt that inappropriate treatment or practitioners' inexperience might have caused their pain to worsen. Others reported unsupportive attitudes or unreasonable expectations from program staff, or that their hopes for recovery were disappointed.

Areas for Future Study

With these preliminary results, ACPA hopes to encourage more research into multidisciplinary pain rehabilitation programs and their outcomes. Although tracking doctor visits and opioid use can help to show part of the picture, these measures do not give the full story of how treatment can affect a person's physical ability and emotional well-being. A detailed assessment of



changes in attitude, ability, and family support relationships could help to determine what types of programs are most helpful. Also, can good outcomes be correlated with the duration of the program, types of treatments used, or specific techniques? These answers could help ACPA advocate for the best types of programs and also guide us in providing “aftercare” resources for program graduates.

Another important area of interest is the medical community's awareness of pain rehabilitation programs. What causes a physician to recommend—or dismiss—pain rehabilitation? How can insurers support programs that truly make a difference? ACPA and its members could benefit from learning much more about these issues.

Interdisciplinary Programs Succeed with Coordinated Therapies

by Alison Conte, Editor, ACPA Chronicle

“The whole is greater than the sum of the parts,” is how Judith Scheman, Ph.D., describes most pain rehabilitation programs (PRPs). Though they describe their offerings differently—multidisciplinary pain control, polymodal pain treatment, comprehensive pain program—these programs operate on the principle that several inter-related therapies, coordinated by a team of professionals, relieve pain and restore function better than any single treatment.

“We aren’t sure why, but outcomes are better for many patients in a team setting,” Dr. Scheman says. She is Program Director of the Chronic Pain Rehabilitation Program in the Neurological Center for Pain, which is part of the Cleveland Clinic Neurological Institute. Dr. Scheman is also co-chairing the American Pain Society’s special interest group on pain rehabilitation programs.¹

Most PRPs have a medical director who is a pain specialist, usually a neurologist, psychiatrist, or anesthesiologist. The physician works in tandem with a registered nurse, physical therapist, occupational therapist, and psychologist or psychiatric counselor, and perhaps a biofeedback therapist, family counselor, acupuncturist, vocational counselor, or massage therapist.

Typically, the coordinated treatment plan incorporates medication, physical therapy, (exercise, occupational, and vocational therapy) and psychological counseling. Some programs offer surgical interventions, while others stress conservative rehabilitation techniques. Ideally, the program is self-contained, away from hospital inpatient activities. Some therapies might be offered in another part of the hospital or a private office.

“Because pain is a biological, psychological, and social condition, treating it with just one treatment is often not as effective as poly-modal treatments,” said Dr. Scheman. “Pain influences function and mood. Very often anxiety and depression are associated with pain.”

People whose lives are devastated by pain are not always aware of the connection between their mental state and physical pain. “They think, ‘if I didn’t have my pain I wouldn’t be depressed,’ but we know that pain is both an emotional and sensory problem, and we can’t separate them from each other,” said Dr. Scheman.

But it is the managed interaction of modalities that keeps the patient’s treatment plan working. “I see a distinction between multidisciplinary and interdisciplinary,” said Dr. Scheman. “In interdisciplinary programs, each therapist knows what the other specialists are doing, and the team is fully aware of the patient’s needs.”

Too Often the Last Resort

In 2006, 305 ACPA members shared their experiences with PRPs through a survey on the ACPA Web site (see page 4). On average they had had chronic pain for 9.5 years and almost all of them had seen three or more doctors to treat their pain, with 55 percent seeing their doctors once a month or more.

“Our participants have spent three to seven years living with chronic pain, and on average, they have seen seven doctors,” said David Provenzano, MD. He is Medical Director of the [Pain Treatment Center](#) at Ohio Valley General Hospital, Pittsburgh and a member of the ACPA Board of

Directors. “I wish they would find us sooner, as early attention can limit the degree and severity of chronic pain.”

“Many people come to us because they have failed at individual therapies,” added Dr. Scheman. “We work together with the person to set goals, such as to decrease pain, to normalize function, and improve mood. The person with pain is the most important member of the treatment team, and sets the goals, but we all know what the others are doing and what the participant is working toward.”

Setting Realistic Expectations

People with pain often seek to return to the days before pain, to a pain-free life, but pain specialists know that is unrealistic. “Pain reduction is the goal, not elimination,” said Dr. Provenzano.

Younger patients, such as those with back pain, want to restore function so they can return to work and daily activities. But if advanced age is a factor, the patient may not be a good candidate for surgical procedures. “There, the goal may be to reduce the degree of pain and help the patient live a more satisfying life, even with their problems,” Dr. Provenzano added.

Eighty-eight percent of the ACPA survey respondents had severe pain before going to a pain rehabilitation program. After the PRP, 54 percent reported improved pain levels and 49 percent said their functioning had improved. Emergency department visits went from 64 percent to 30 percent.

While this shows a level of improvement for many, it also leaves about half of respondents without significant reductions in pain or increases in functioning. According to Dr. Dennis C. Turk, Ph.D., Chairman, Department of

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Seek a multidisciplinary program. Pain is both an emotional and sensory problem.

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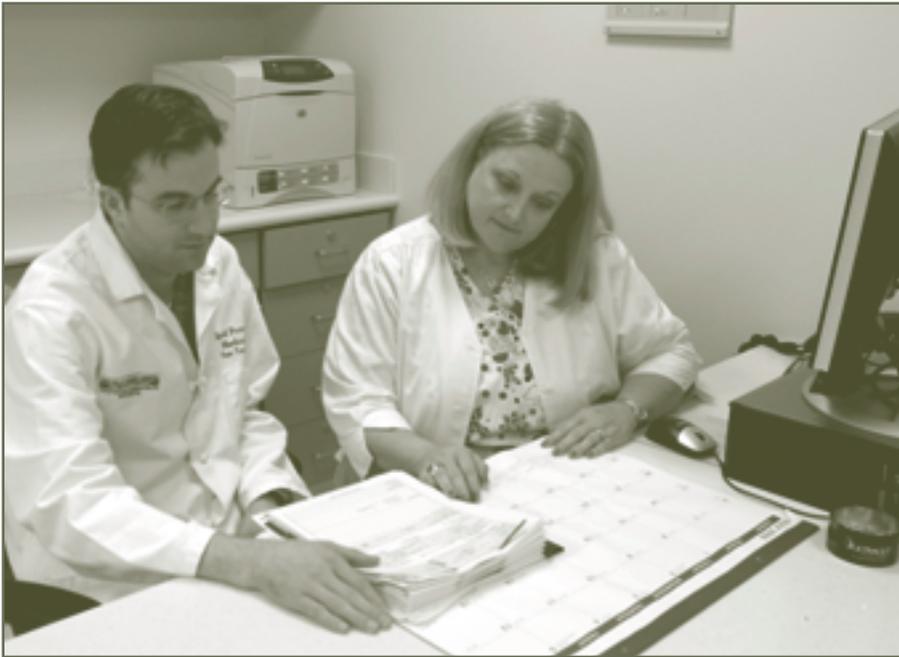


photo by Amelia Conte

Dr. David Provenzano confers with Gaye Jarzabek at the Pain Treatment Center at Ohio Valley Hospital.

Anesthesiology, University of Washington, Seattle, this is on par with many other methods of pain treatments including prescribed opioids.

Dr. Turk's analysis of many studies on pain revealed that even when medications work well for a person with pain, they rarely reduce pain below a rating of 4 on a scale of 1-10 with 10 being the highest level of pain. Only 30 to 40 percent of patients reported at least a 50 percent reduction in pain.²

Understanding the PRP Process

"We begin with an informational meeting with the treatment team, during which we explain the process and discuss what participants can expect over the course of their visits," said Gaye Jarzabek, RN, Director of the Pain Treatment Center at Ohio Valley Hospital.

But the participants also need to understand what they are getting into. As Dr. Provenzano said, "I tell my patients, particularly my SCS (Spinal Cord Stimulation) patients, that this is an ongoing relationship. You and I are going to be long-term friends, with responsibilities to each other."

Though many health insurance plans pay for only 12 weeks of physical therapy, this can be too short a time to make headway against years of inactivity caused by chronic pain. So therapists teach exercise regimens to be continued at home, a discipline that program participants must be prepared to accept.

While some participants are successfully discharged from PRPs, many should prepare for ongoing follow-up for many years. Often, medications levels must be adjusted as people learn to manage

their pain with other modalities and feel the results of their physical rehabilitation and counseling therapies.

Dr. Provenzano said that he initially sees his SCS patients monthly in the early recovery stage to fine tune their implants and optimize the coverage area for pain relief. "When we provide interventions and medications, we always close the loop, plan a follow-up visit, call the next day, and a week later," said Jarzabek.

Evaluating a Pain Program

If you live near a large city, look for hospitals and rehabilitation centers that offer comprehensive, interdisciplinary pain treatment. Consumer guidelines to selecting a PRP are on the ACPA Web site under [Managing Chronic Pain](#).

Other resources for listings of pain physicians and PRPs are:

- * The American Pain Society, (847-375-4715) National Pain Foundation's [Caregiver Directory](#)
- * The Commission on Accreditation of Rehabilitation Facilities (CARF) (800-281-6531) for accredited pain programs in your area.

Gaining CARF accreditation can be an expensive and time-consuming process, so some high-quality pain programs that are trying to maintain financial stability may not elect to attain CARF accreditation. Be sure to check with your health insurance as it may require that the unit be CARF accredited for you to receive reimbursement.

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PRP directors suggest you consider these factors when reviewing pain clinics.

- * Seek a multidisciplinary program.
- * Avoid programs that just offer one modality, such as injections or physical therapy.
- * The medical director should be a pain management specialist.
- * The staff should be attentive and involve you in determining goals and setting a treatment plan.
- * The staff should be willing to discuss the financial realities of your health care plan and ways to make it more affordable.
- * The program should offer follow-up visits after the initial course of treatment.
- * They should provide access to professionals, welcoming questions and phone calls.
- * The program should be convenient for you and your family, as you may need to attend daily or several times a week.
- * If part of a hospital or rehabilitation center, the program should be housed in a separate unit designed for pain management.

Do It Yourself?

Not everyone has access to a pain rehabilitation program, but there are ways to gain some of the benefits of a multi-modal treatment plan in your own pain management. Education and communication are essential.

“Learn about your pain and your condition,” said Dr. Scheman. “Chronic pain is not the same as acute pain, so don’t let your doctor treat it that way. Chronic pain is not a fire alarm, it’s an error message.”

People with pain must assert their right to good treatment. “Don’t turn all of your power over to a white coat. And don’t turn all your power over to the pain,” she added.

* **Communicate.** Make sure that your various caregivers are all communicating with each other and are aware of what other treatments are given and how they interact. Write down and share your observations, daily

function increase or decrease, activities, moods, emotions, pain levels, and medication side effects. Share these with each doctor or therapist at each appointment. The ACPA has [communication tools](#) to help you track your pain and keep your doctor informed.

* **Medication.** Record your reaction to changes in medications. Develop a plan with your physician to set a number of weeks for each adjustment to produce results. If you haven’t seen a decrease in your pain levels, or cannot tolerate side effects, you and your doctor should try an alternative.

* **Counseling.** Consider how a psychologist could help you manage your emotions and improve your mood, which could decrease your pain. Ask your primary physician to refer you to a mental health counselor.

* **Physical Fitness.** Ask for exercises that you can do at home to stretch your muscles and get in shape. A person in good physical condition will have less pain.

* **Stress Reduction.** Try meditation, relaxation tapes, or guided imagery to control your brain’s reaction to pain. Find absorbing hobbies that help you take a vacation from pain. ACPA now has a five minute [relaxation video](#) available at <http://www.theacpa.org/people/videos.asp>.

Pain management is a lifetime process. To regain control of your life, it is important to learn how to cope with chronic pain. Pain rehabilitation programs, and the principles they practice, have improved the quality of life for many people with pain.

1 The Pain Rehabilitation Special Interest Group of the American Pain Society is for those with an interest in multidisciplinary programs targeting rehabilitation in chronic pain patients. Co-chairs are Judith Scheman Ph.D. and Cynthia O. Townsend Ph.D. of the Mayo Clinic. The group’s 2008 Annual Meeting Presentations about the Adolf Meyer Chronic Pain Treatment Program and the Mayo Clinic Pain Rehabilitation Center are available at the [APS Web site](#).

2 Efficacy and Cost-effectiveness Treatment for Chronic Pain: An Analysis and Evidence-based Synthesis, Dennis C. Turk, Ph.D. and Kimberly Swanson, M.S., University of Washington. Published in: Schatman ME, Campbell A. eds. Chronic Pain Management: A Guidebook for Multidisciplinary Program Development. New York: Informa Healthcare; 2007:15-38.

Despite Good Results Pain Programs are in Decline

by Alison Conte, Editor, ACPA Chronicle

Despite their success in reducing pain and improving lives, many PRPs have closed in recent years. This decrease may be due to the current economic realities of health care delivery. “It is difficult to be financially viable,” said Dr. David Provenzano. “Academic-based centers have struggled to provide all the services in a cost-effective manner.”

Third-party payers—both Medicare and commercial insurers—typically reimburse physical therapy at lower levels than surgery and other procedures and often don’t cover a long-term regimen. Hospital-based pain centers are less negatively affected because costs are distributed throughout the system and the less-profitable pain centers can be “carried” by medical services that are reimbursed at higher levels.

“Treatment centers are driven by the need to be sustainable, if not profitable, so they can only survive if they are part of an institution that can afford to sustain them,” explained Dr. Judith Scheman. “At hospitals, pain centers can offer pain management tools that are an alternative to surgery.”

Effective and Cost Effective

Dr. Dennis Turk reports that despite the high cost of treating chronic pain and the advancements in medicine, relief remains elusive. “Total elimination of pain is exceedingly rare, which is why it is called chronic pain,” he said.¹

“For many patients, surgery for back pain brings relief, but for others, it just brings on more back pain,” he said. SCS, epidural infusions, and other implants are considered successful when about 50 percent of the patients report at least 50 percent relief of pain.

We know that almost no treatments “cure” chronic pain, and even patients at successful multidisciplinary pain rehabilitation programs (PRPs) report pain reduction of 37 percent.

“Interestingly, the pain reduction achieved at PRPs is accompanied with significant decrease (63 percent) in prescription pain medication,” he said.

“If the results indicate that disparate treatments produce roughly the same outcome, then the issue of cost becomes especially relevant.”

Consideration of the data reviewed suggests that PRPs are substantially more cost-effective than the alternatives. For example, the cost of one patient achieving the average reduction in pain for PRPs would be \$30,678 compared to spinal surgery that would cost \$55,154. Based on these figures, PRPs would create the same outcomes at less than one-half the cost (actually 44 percent of the cost).

Support for a Change

Organizations that support people with pain have come out in favor of better financial compensation for PRPs. In 2005, the American Pain Society’s Task Force on Comprehensive Pain Programs sought to alert insurance companies and other third-party payers to the potential benefits of multidisciplinary pain programs.

The APS paper stated that, “the only therapeutic approach that has shown efficacy and cost-effectiveness is a comprehensive pain program with functional restoration as a primary goal.” Despite the effectiveness and efficiency of PRPs, third-party payers “continue to resist reimbursement for the expenses of these rehabilitation

programs and . . . have instituted many cost-cutting mechanisms, which have actually steered patients away from treatments that demonstrably reduce health care utilization and towards more expensive therapies with poorer outcomes.”²

Additional research, education, and legislative action will be needed to rectify this situation and make pain reduction—with all the accompanying benefits for productivity and society—a priority for health insurance firms and Medicare.

1 Efficacy and Cost-effectiveness Treatment for Chronic Pain: An Analysis and Evidence-based Synthesis, Dennis C. Turk, Ph.D. and Kimberly Swanson, M.S., University of Washington. Published in: Schatman ME, Campbell A. eds. Chronic Pain Management: A Guidebook for Multidisciplinary Program Development. New York: Informa Healthcare; 2007:15-38.

2 Evidence-Based Scientific Data Documenting the Treatment and Cost Effectiveness of Comprehensive Pain Programs for Chronic, Non-malignant Pain, American Pain Society. APS Task Force on Comprehensive Pain Rehabilitation Report by Robert J. Gatchel, Ph.D. ABPP, and Akiko Okifuji, Ph.D.; APS Bulletin, Volume 16, Number 1, Winter 2006.



A Better Understanding of Chronic Pain

Assessment Tools Reveal Multiple Dimensions of Treatment

by Gail C. Davis, RN, EdD

Developing better ways to assess chronic pain is important to medical professionals and people with pain alike. Over the last year, 200 people responded to a pain study linked to the ACPA Web site. I thank them for contributing to a better understanding of what it's like to live with persistent pain and how it's managed.

The study revealed that using a variety of pain management methods—as practiced by pain programs—is important. Some methods may be viewed as more helpful than others, but every person experiencing chronic pain needs to have a combination of methods available for use at any time.

The major objective of the online study was the refinement of a tool for assessing the experience of living with persistent pain. In addition to responding to the Chronic Pain Experience Instrument (CPEI), individuals also completed a General Information Form (GIF), the Pain Management Inventory (PMI), and the Pain Management Outcome Expectations Instrument (PMOEI).

The average age of respondents was 44 years, with ages ranging from 27 to 84; 127 were female and 47 male. The most common pain-related diagnoses (noted by over 15%) were back pain (41%), fibromyalgia (32.7%), neck pain (30.7%), osteoarthritis (21%), sciatica (19.5%), and peripheral neuropathy (18.5%). The average length of time that pain had been experienced was 10 years with a range of 6 months to 48 years. Pain intensity and management were each rated on a scale of 10, with average intensity at time of responding rated as 6.18 and how well pain was managed as 4.29.

Three components of the chronic pain experience emerged from this testing of the CPEI: * *Interference with Function* * *Distress* * *Helplessness*

Scale	Total Score Possible	Average Score Obtained
Interference with Function	55	16.44
Distress	55	24.31
Helplessness	33	13.20
CPEI Total	143	53.99

(The higher the total score and the component scores, the better the experience of living with pain)

Results show that the overall experience of living with pain can be assessed and that this assessment gives some direction to the individual and the healthcare professional for managing the pain. As the figures above indicate, pain's interference with function seems especially difficult for individuals. For example, pain is a "constant struggle," interfering with participation in enjoyable activities as well as with carrying out responsibilities.

Distress refers to being tense, experiencing anger when in pain, and being irritated by little things. Helplessness is exemplified by asking Why me?, generally being afraid the pain will get worse, and crying (or feeling like crying) when pain is at its worst.

Different Ways of Looking at Pain Management

The Pain Management Outcome Expectations Instrument addresses the person's confidence that a pain management method will have a positive outcome. Users rate items such as: "If I plan my activities so that I don't become overly tired, I can better manage my pain."

The total scale of 11 items has a possible total score of 121. The average score of the respondents was 58.44, indicating that the overall confidence level is just about half for methods such as pacing

activities, distraction, taking a warm tub bath or shower, relaxing, and getting a good night's rest to manage pain.

The Pain Management Inventory lists 15 pain management methods, and the respondent is asked to rate each one according to how often it is used (1 = never use to 6 = often use) and how helpful it is (1 = not helpful to 6 = very helpful). Here are the methods rated greater than 3.5. They are ranked from used most often to least often:

1. Prescribed medicine
2. Distraction
3. Pacing activities to avoid overdoing
4. Heated pool, tub, or shower
5. Prescribed antidepressant medicine
6. Positive self-talk
7. Heat application
8. Stress-control methods
9. Massage

While almost everyone used prescribed medicine, distraction, pacing of activities, and heated tub or shower, we found that the use of massage, stress-control, heat application, and self-talk was spread out more evenly among the sample. Prescribed antidepressants showed a split between those who never used this method and those who used it often. This would make sense, since antidepressants are more commonly used for certain types of pain.

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How Much Do Methods Help?

Only four methods received average “helpfulness” ratings of 3.50 or greater:

1. Taking prescribed medicine (4.07)
2. Support offered by personal religious beliefs (3.93)
3. Using a heated pool, tub, or shower (3.68)
4. Pacing activities (3.54)

Methods such as distraction, massage, stress-control, heat application, and self-talk seem to represent moderately helpful methods that the majority of individuals use. Using a combination of the pain management methods available is the key to reducing pain for most people.

Multidimensional Pain Requires a Range of Response

It's important to look at each person as an individual. The pain-related diagnosis, type of work one does, work and family responsibilities, support system, and pain intensity affect how pain is experienced and managed. Persons need to have a number of different methods that they are comfortable using and can draw from at any time.

Some pain management methods, such as relaxation techniques and exercise, require some learning and practice. Individuals may need to ask for education in these techniques or a referral to another type of practitioner.

Chronic pain is multidimensional in nature. This study underscores the importance of approaching its management from a perspective that addresses its many facets.

Management refers not only to pain relief or decreasing the intensity of pain. It refers also to acquiring skills that will enable one to soften its effects and to live with it more successfully. Believing that the methods selected will work is an important part of achieving success.

For complete [survey results](http://myweb.twu.edu/~gdavis/index.html), go to <http://myweb.twu.edu/~gdavis/index.html>.

Gail Davis, RN, EdD, is a professor at Texas Woman's University and a member of the ACPA Professional Advisory Committee.

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Driving with Four Flat Tires

CONTINUED FROM PAGE 1...

Unlike traditional medicine where the “patient” is a passive recipient, living a full life with pain requires that we take an active role in the recovery process. We need to work with our health care providers to find what we need to fill up our other three tires. The answer is different for each of us, depending on our individual medical and personal needs. Biofeedback, physical therapy, counseling, pacing, nutritional counseling, and a host of the medical modalities are but a few of the ways we can fill up our tires.

In this issue of *The Chronicle*, we will look at pain management programs that provide a wealth of resources to help people with pain fill up their tires.

Twenty-nine years ago I went through a pain management program that guided me through a complex maze of coping skills and interventions. For the first time, I received all of the therapies I needed in an integrated program. Though one therapy didn't work by itself, when I combined it with others I began to experience true changes in my ability and function. It allowed me to fill up all of my tires and gave me the ability to maintain my “car” long term.

Living with pain is not easy, but it is possible. If you take the wheel—by fully participating in your treatment plan—and remain flexible as to the route you need to follow, the journey can be a positive one with personal discoveries and enhanced awareness of life itself. We invite you to come along with us as we explore the world of pain management programs.

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ACPA Update

New ACPA Groups

Welcome to our new groups and facilitators.

Angela Scott
Riverside County, CA

Phillip McDowell
Jacksonville, FL

Dr. Robert Yeziarski
Gainesville, FL

Mara Gerke
Adams County, IN

Donna Giessinger
Flint, MI

Tricia Drummond-Sweeting
Edgecombe County, NC

Radha Collins
Portland, OR

Lisa Thompson
Anderson, SC

Richard Follette
Renton, WA

Regional Directors to Meet for Pain Awareness Month

The Regional Directors Leadership Conference will be held on September 12-14 2008, in Chicago, Illinois. This event will provide facilitators of ACPA support groups around the world with reinforcement of ACPA principles, advice for better group management, and the opportunity to build peer support networks. In addition, the workshop will include updates on pain-related news and events and advocacy skills training to help facilitators speak out more effectively.

Donate to the ACPA through CFC

The ACPA has been accepted as an approved charitable organization for the Fall 2008 Combined Federal Campaign (CFC) as a member of Health & Medical Research Charities Of America. The ACPA agency code is 10549. This code only applies to CFC—the world’s largest annual workplace giving campaign involving federal civilian, postal, and military donors.

If you work for a CFC organization, or know someone who does, please use this number to identify ACPA as the recipient of your gift.

New on the Web: Fibromyalgia Help

People who live with chronic widespread pain from Fibromyalgia can learn more

about their condition at the ACPA Web site with the *Fibromyalgia Tip Sheet* and *Fibromyalgia: The Information and the Care You Deserve*. These educational materials were created cooperatively by the ACPA, the American Pain Foundation (APF), and the National Pain Foundation (NPF). Pfizer, Inc. is providing a charitable donation to support organizations that help people with pain, including The National Fibromyalgia Association, ACPA, APF and NPF. For each visitor who logs in to www.FibroCenter.com and promises to learn about fibromyalgia, Pfizer will donate \$1—up to \$100,000. Please visit www.FibroCenter.com; your pledge helps us all to educate and support people living with pain.

IMMPACT Study Published

Identifying Important Outcome Domains for Chronic Pain Clinical Trials: An IMMPACT Survey of People with Pain, has been published in *Pain*, the journal of the International Association for the Study of Pain. The study was headed by Dennis C. Turk, Ph.D., University of Washington. It was based in part on responses from 959 participants who answered a survey on the ACPA Web site. You can find the article at <http://dx.doi.org/10.1016/j.pain.2007.09.002>. An article about the study was printed in the Fall 2007 issue of *The Chronicle*.

Using the Internet to Gain Knowledge

“How do you use the Internet for help with chronic pain?”

In Spring 2008, visitors to the ACPA Web site answered that question this way:

Number of respondents	Answers
5946	To research my condition
2948	To learn about new treatment options
2472	To communicate with public officials about pain issues
1284	To find doctors or other health care professionals
739	To connect with others with pain
585	To find inspiration and encouragement

Medical Update

Arthritis Medication Guidelines Updated

Rheumatoid Arthritis Medicines: A Guide for Adults, and *Choosing Medications for Adults with Rheumatoid Arthritis* are now available in print or online at <http://effectivehealthcare.ahrq.gov>. (Click on Summary Guides and then scroll down to select a topic.)

This guide for clinicians compares the benefits, risks, and costs of different rheumatoid arthritis drug treatments. The guides are created by the Effective Health Care Program, a division of Agency for Healthcare Research and Quality.

Health Information Translations

The Exchange is a resource of health news and information translations at www.health-exchange.net. It houses 2,500 PDFs of translated materials in 14 languages on topics that range from mental health and pediatrics to x-rays.

The archive is available to members only, but Patient Link members have free access to it, thanks to the Medtronic Foundation. Click on “For Members: Translation Library” on the lower left hand corner of the home page or go to www.health-exchange.net/material/materials.php. Enter “Patient” as the login name and “Link” as the password.

Ask Questions

We’ve all been there. At the doctor’s office, as your appointment comes to a close, he or she asks, “Do you have any questions?” All too often, nothing comes to mind. You might be overwhelmed by the news of an upcoming procedure or confused by the addition of a new medication and later—too late—lots of questions arise.

The Agency for Healthcare Research and Quality, can help. Questions are the Answers (<http://www.ahrq.gov/questionsaretheanswer/>) has a list of common questions that will help your doctor understand your concerns and reveal important medical issues that can affect your health and your treatment.

The site also has a Question Builder to customize a list of questions, depending on your situation. Don’t miss the video, with its memorable, musical message.

Here are some of the most common questions that patients should ask:

1. What is the test for?
2. How many times have you done this?
3. When will I get the results?
4. Why do I need this surgery?
5. Are there any alternatives to surgery?
6. What are the possible complications?
7. Which hospital is best for my needs?
8. How do you spell the name of that drug?
9. Are there any side effects?
10. Will this medicine interact with medicines that I’m already taking?

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

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Tributes

In Memory of JOE MENSOR

GIVEN BY SAMANTHA NAGY

Joe Mensor, a facilitator for the ACPA for more than 10 years, passed away on May 12, 2008, from lung cancer. According to Ed Krappmann, who was co-facilitator with Joe for the Metro East support group in Detroit, Michigan, Joe was an all-around good guy who will be deeply missed.

“He was genuinely interested in helping people along their journey with chronic pain. Unable to work for many years, he dealt effectively with CFIDS, fibromyalgia, and closed head injury,” said Ed.

When interviewed in 2006 for the ACPA *Chronicle*, Joe described his primary purpose as helping others who were worse off, often taking his support group members for doctor appointments, picking up a prescription, or just calling to see how they were. He said, “This allows me to be aware of how blessed I am to be able to give them a hand.”

In Memory of DR. HUBERT ROSOMOFF

Long-time member and past president (1992-1993) of the American Pain Society (APS) Hubert L. Rosomoff, MD, DMedSc, died on June 5, 2008 at age 81.

Dr. Rosomoff, was founder of The Rosomoff Comprehensive Pain and Rehabilitation Center and is widely recognized as a world authority on pain and its treatment. He pioneered investigation of hypothermia for intracranial vascular surgery and developed techniques of cryosurgery and innovative surgical procedures for the spine.

In a 2004 interview with the APS *Bulletin*, he called the non-interventional multidisciplinary approach to pain, of which he was a pioneer, the “hallmark of pain medicine.” He was a leader in APS, International Association for the Study of Pain, the Eastern Pain Association, the American Academy of Pain Medicine, and the Southern Pain Society.

Thank You!

Since 1980, the American Chronic Pain Association has provided people who must live with daily pain a means to help themselves to a richer, fuller life. 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. Your membership, donations, and purchase of materials keep the ACPA alive and reaching out to even more people with pain.