



# CHRONICLE



## The Financial Costs of Pain

by Penney Cowan, Executive Director, ACPA

### INSIDE

- 2 [Living Well with Less](#)
- 4 [When Chronic Pain Hurts Your Wallet](#)
- 5 [Get Help with Financial Issues](#)
- 6 [Adjusting Your Financial Future](#)
- 7 [Medical Briefs](#)
- 8 [Economic Casualties of War](#)
- 9 [Insomnia and Chronic Pain in Adolescents](#)
- 10 [ACPA Updates and New Groups](#)
- 11 [Essay](#)
- 12 [Book Review](#)
- 13 [Members' Forum](#)
- 14 [Tributes](#)



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The Institute of Medicine recently published the report *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. One of the findings that many will find shocking is the financial cost of pain.

The report states that at least 116 million U.S. adults are burdened by chronic pain. The annual cost to the national economy associated with chronic pain is estimated to be \$560 to \$635 billion. That is more than heart disease, cancer, and diabetes combined! (This estimate includes the cost of health care for those with pain and the cost of lost productivity attributed to pain.)

We are all aware of the impact pain has on our bodies. We also know that pain can have direct effect on our family and friends. Pain can isolate us from those who mean the most to us, the people we look to for support, encouragement, and understanding. But pain can also affect our financial health, which becomes a contributing factor to how well we are able to cope with the many burdens and limitations pain places on us.

#### **Losing Gainful Employment**

Those who were working when pain entered their lives experienced a major shift in status and lifestyle. It is often difficult if not impossible to continue



working because of the pain. For many, their jobs provide health insurance along with a regular paycheck. With limited ability to earn a living, and health coverage uncertain, there can be significant changes in our access to the things we need most: health care, food, and shelter.

When we are no longer able to have steady employment, we might look to disability to help with expenses. But obtaining and retaining disability is not an easy task and can take a long time. While we are waiting, we can run out of money for car payments, house payments, or rent. Far too often, families break up under the emotional, financial, and physical burdens of having a spouse with chronic pain.

What is the final cost of all these losses? Often it is more than anyone is willing to pay or can afford.

CONTINUED ON PAGE 5...

**September is Pain Awareness Month.**

See our [website](#) for related news.

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# Living Well with Less: Budgeting for Chronic Pain

by Erin Kelly

People often speak of the emotional or physical “cost” of having chronic pain—but the financial cost is real too, and it can be devastating.

“It’s very expensive to be ill,” says Missy Oesterheld, an ACPA facilitator in Fredericksburg, Virginia. Even with insurance, her out-of-pocket costs add up. “I take 10 medications every day,” Oesterheld says, noting that eight of those are absolutely necessary and the others—a muscle relaxer and a pain medication—are not things she’d willingly go without. And some pain treatments are not eligible for insurance. “Massage therapy seems to help me the most, so I do that two or three times a month,” Oesterheld explains, “but that’s an extra \$200 a month.” Even the price of books and medical journals that she buys to educate herself about new research and treatment opportunities take a financial toll.

## Practical, Inexpensive Solutions

But there are also inexpensive therapies that can be very helpful. “I swear by my heating pad and my electric blanket,” says Oesterheld. “I have extras that I keep at work.” She also routinely puts on warm sweaters and socks to keep her joints warm at night when the temperature drops. She says she gets strange looks sometimes, but isn’t discouraged. “It’s 100 degrees in Virginia today, and I’m at my desk with my heating pad!”

She uses Epsom salts to soothe her muscles, peppermint to settle her stomach, and lavender aromatherapy to help her sleep. “You can get a big bag of Epsom salts in the drug store for about \$5,” Oesterheld points out.

Judy Gober, a longtime ACPA facilitator from eastern Pennsylvania, also has relied on low-tech aids to cope with chronic pain. “You can buy risers for your bed’s feet to make it easier to get

in and out of—they’re about \$10,” she says. “I have a \$20 knee brace from the drug store; I think it’s helped me put off having knee surgery and allows me to go longer between cortisone shots.”

Gober recommends a mechanical “grabber” to extend one’s reach without stretching, a booster for the home toilet seat to ease the stress on your back and knees, and small stepstools for getting in and out of high vehicles. “My roommate at the ACPA Advisory Board meeting had a microwaveable hot/cold pack she traveled with,” Gober says. “If you’re at a restaurant you can ask them to heat it up for you.”

## Finding the Medical Care You Need

When it comes to chronic pain relief, a heating pad won’t do everything. Professional medical care is essential.

ACPA facilitator Terry Witty, who lives in New Port Richey near Clearwater, Florida, has learned to find her way through many benefit programs available to underinsured people. She’s also learned that what’s available can change drastically from one state’s programs to another.

“I qualified for Medicaid in Michigan, but when my disability application was approved I moved to Florida to be near family. Florida is like a different world,” she says. Witty learned that as a single-person household she couldn’t get Medicaid in her new home. Undaunted, she researched low-cost care and found a free medical clinic nearby. “Through the clinic I got approved for a program that helped pay for prescription drugs,” she says. “When I got my own apartment, I moved to a different county and the rules were totally different,” she says. “Here all my medications are free, but I can’t see a specialist.”

“You have to do your own research,” Witty says. “I’ve always gone to the doctor with a list in my hand.”

She’s found many low-cost medical programs on the Internet. “I search for ‘free health clinic’ or ‘prescription help,’” Witty explains. “And I don’t give up.”

Discounted care is useful whether you have health insurance or not. Oesterheld has medical insurance that covers some of her expenses, but she also takes advantage of discounts when they’re available. When she started on a new arthritis medication, her rheumatologist helped her enroll in the pharmaceutical company’s program that gave her discounted medication for a year. Gober buys one of her most expensive medications from a Canadian pharmacy service—at a cost savings of more than \$4,000 a year.

Witty has had to forgo some treatments because she doesn’t have the insurance to cover them. Only recently was she able to get fibromyalgia medication through the clinic and is looking forward to qualifying for Medicare in November 2011. “I have a muscle relaxant for cramping, but it knocks me out,” she says. “I still have muscle aches and I can’t concentrate. But it’s all I can do for now.”

## Insurance Concerns

Over the years, Gober has learned to tread carefully when navigating insurance systems. When her pain problems started, she tried to keep working. “I waited two years to apply for social security disability payments, and then I only qualified for the minimum because I hadn’t paid enough in,” Gober explains. The time she took off work to recover from surgeries had impacted her earnings.

“A lot of people go through this,” she explains, “There are times when you’re not well enough to work, but not bad enough to not work!” She also had to use some of her benefit to pay back a lump sum distribution from her short-term disability insurance.



*“There are so many things you can do that don’t cost money.”*

CONTINUED FROM PAGE 2...

Health insurance is a tricky situation for people with chronic pain. “If you use a lot of medical services, you really might need to spend more on a health care plan,” Gober says. The Medicare co-insurance plan that she chose has a high monthly fee but covers doctor visits completely and includes a generous prescription plan. “It ends up that I’m better off with the more expensive plan,” Gober says. “Last year I hit the ‘donut hole’ in July,” she says, referring to the Medicare benefit limit for prescription drugs. “This year, so far, I’m okay.”

Gober learned a few other tricks along the way. When her husband retired, they weren’t old enough to qualify for Medicare and they bought COBRA insurance. “It was ungodly expensive!” Gober says, “but it turns out that if you move from COBRA to private insurance you can get coverage for preexisting conditions.”

And it’s not just health insurance that requires careful planning. Because of her health history, Gober and her husband had assumed that he would likely outlive her. “When we bought our house, we got life insurance on me that would have paid off the mortgage,” she says. “As it turned out, he was the one who

passed away first.” Gober faced the prospect of giving up her home after her husband’s death, but was able to work out a solution when her son and his family decided to share the home with her. “You just never know,” she says.

### ***Enjoying Life with Less***

Gober raised a family while managing her chronic pain. But giving up her income forced her to become creative about entertaining—and feeding—her family of three boys. “I became a master at stretching a dollar and finding ways to do things for less,” she says.

Oesterheld is lucky enough to be able to continue her full-time job, but she has made lifestyle changes because of the cost of chronic pain. She used to enjoy “retail therapy” as a way to cheer herself up on a bad day, but shopping stopped being fun when she couldn’t afford the extra purchases or the stress on her body. “Spending hours at the mall just doesn’t work for me,” she explains. “Communicating that to my family has been one of the hardest things to do,” she adds. “I’ve had to learn to say no.”

But Oesterheld points out that you don’t need to spend money to make yourself happy. She suggests making a list of 10

things that make you happy. “Make the list when you’re feeling good,” she says. These can be as simple as warm socks, a hot bath, spending time with your pet, or a peppermint candy. Then when you’re not feeling good, indulge in an item from the list.

Gober has developed a large repertoire of ideas for low-cost fun. “There are so many things you can do that don’t cost money,” she says. When her children were young, she scanned the newspapers and went to high school plays, Easter egg hunts, picnics in the park and Santa’s workshop events. They all had library cards. Adults can also seek out and enjoy these community activities.

“You have to be creative,” Gober says. “We had sleepovers, and the kids would watch a movie or bake cookies. That doesn’t cost much. You can have them make water balloons; all you need is a one-dollar bag of balloons and a hose!”

“The smartest thing you can do is to have friends with a pool,” Gober jokes. But she has tips for that lucky situation too. “Don’t take advantage of them,” she says. “Bring your own towels and bring snacks to share. Make sure you’ll get invited back!”

The idea of using friends and relatives for entertainment instead of movies and video games may be old-fashioned, but it’s not outdated. “All the things I did with my kids I now do with my grandchildren,” Gober says. “With my 3-year-old grandson, I take him for a walk and spend time with him. We catch lightning bugs and watch the moon.”

Whether you’re trying to entertain a family or just pay for your medication, the challenges of living on a pain-limited budget can be discouraging. But they also can be solved with research, persistence, and creativity. And ACPA can help you find people who’ve faced the same problems and can share their solutions.

# When Pain Hurts Your Wallet

by Alison Conte, Editor, *The Chronicle*

Chronic pain doesn't play fair. Not only is your body hurting, your energy depleted, and your emotional state fragile, this unwelcome guest may even have drained your bank accounts.

Living with pain can result in bills for increased hospital and doctors' visits, medication, travel, physical therapy, mental health counseling, rehabilitation programs, assistive devices, special beds, household help, and home health aides. Health insurance coverage can be insufficient, particularly when a diagnosis isn't fully covered. You may have to pay directly for alternative medical treatments like acupuncture, special foods and vitamins, or "experimental" procedures.

And on the income side, chronic pain can affect your ability to work at your chosen career. Giving up a job often means losing income and health benefits.

But the financial impact of chronic pain must be approached in much the same way as you approach the emotional and physical aspects.

Just as you changed your life to manage your pain, you may need to change your life to adjust to new economic realities. And in the same way that you work with your healthcare team to manage your pain, you must take an equally active role in controlling your finances.

## Get Help to Plan Ahead

This means looking out for the long term, working with a financial planner, your insurance company, employers, and perhaps a debt counselor. It is essential to organize your finances, spending, and budgeting responsibly. (See [page 6](#) for more on this subject.)

"You may have to accept a reality of life with less money," said Jennifer Christian, M.D., President of Webility Corporation and ACPA board member. "Just as you are accepting a new reality of health, you will have to understand that your new normal is a different financial status from what you were used to."

According to Dr. Christian, if your pain is due to a progressive condition—one that will increasingly limit your income or require additional expenses—you need to do some planning for the future.

## Keeping a Job

If chronic pain has made it impossible for you to keep a job that has demanding physical requirements, don't assume you'll be able to quit and live on disability benefits. According to Dr. Christian, only half the workforce has disability coverage through their work.



"The amount you are paid on disability is related to how much you've paid into it. Sometimes if you have chronic pain but not objective evidence, it can be hard to get and keep disability benefits," said Dr. Christian. "Policies often will cover you for just two years. You may not be entitled to receive full benefits if you have the ability to do another job."

Dr. Christian recommends you "fight like a tiger" to keep your job, seeking accommodations, fewer hours, or less travel. She suggests you talk with your employer about how you can contribute without aggravating your pain or stamina. "Being unemployed leads to worse problems, emotionally, socially, and psychologically," she said. "If you will have a progressive loss of function, develop a strategy in concert with your employer as to what the future is going to hold."

## Living Frugally

If a larger share of your income is going to medical bills and medication, you will want to find ways to live frugally. Can your family get along with one car and use public transportation occasionally?

Living Frugal Tips at [www.livingfrugaltips.com/](http://www.livingfrugaltips.com/) has more suggestions for making the most of your money.

You can find financial assistance resources through the ACPA, at [www.theacpa.org/57/LifeResources.aspx](http://www.theacpa.org/57/LifeResources.aspx).

| TOP |

# Resources for Help with Money Issues

## Some other ways to add fun and purpose to your life without emptying your wallet.

- \* Borrow books, movies, and music from your local library.
- \* When you are able to get out, go to museums during the discount days and movies during bargain matinee showings.
- \* Attend free community events and college lectures.
- \* Go people watching over a picnic in your local park.
- \* Shop garage sales and resale stores for bargains.
- \* Give homemade crafts and baked goods as gifts.
- \* Instead of buying new, reuse, recycle, and repurpose – it's good for you and the environment!
- \* Trade services, like babysitting and gardening, with neighbors and friends.

## The Financial Costs of Pain

CONTINUED FROM PAGE 1...

Older adults who have worked their entire lives and saved for a comfortable retirement fall on hard times when pain invades what they thought would be their “golden years.” The golden years become tarnished and everyday life is very challenging.

Savings dwindle away because of high medical costs that Medicare does not cover. Prescription costs wipe out a nest egg. Plans to travel, relocate, or simply live comfortably and afford everyday things vanish in an instant because of the tremendous pressure pain exerts on financial security. All dreams of enjoying the fruits of a life of labor, the harvests of a lifetime of hard work, seems to be gone all because of pain.

But just as we've learned to take an active role in our medical treatment, learned to adjust our emotions, stamina, and attitudes in light of living with pain, we can pro-actively cope with the financial impact of pain.

In this issue we are going to look at preparing for a financial future that is affected by pain. We will offer resources for those with financial problems and share stories from those who have survived economic woes, so you can get the most out of your life, even when money is tight.

(ACPA will review *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research* in a future issue of *The Chronicle*. To read it now, visit <http://www.iom.edu/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx>.)

**California Help Center** at the Department of Managed Health Care advocates for California residents regarding health care benefits, health plans and member complaints. <http://www.hmohelp.ca.gov/default.aspx>

**Center for Medicare Advocacy, Inc.** provides education, advocacy, and legal assistance to help older people and people with disabilities obtain Medicare and necessary health care. <http://www.medicareadvocacy.org/>

**Families USA** is dedicated to high-quality, affordable health care for all Americans and is an effective voice for health care consumers. <http://www.familiesusa.org/>

**Needy Meds** is a non-profit that helps people who cannot afford medicine or health care costs; anonymous and free of charge. <http://www.needymeds.org/>

**Patient Advocate Foundation** provides mediation and arbitration services for medical debt crises, insurance access, and employment issues. <http://www.patientadvocate.org/>

**RxAssist** is a pharmaceutical access information center by Volunteers in Health Care (VIH), a national resource center for safety net organizations. <http://www.rxassist.org/>

**Partnership for Prescription Assistance** helps people without prescription drug coverage get free or low-cost medicines through prescription medicine assistance programs. <http://www.pparx.org/>

**Prescription Drug Assistance Programs** (American Cancer Society) <http://www.cancer.org/Treatment/index>

| TOP |

# Adjusting Your Financial Future

by Heather Murray

*Editor's Note: Living with chronic pain can often mean living with less: less energy, less stamina, less certainty, and less money. We asked a financial expert to discuss how people with pain can better manage their finances. (The ACPA does not endorse nor recommend specific financial strategies.)*

It's impossible to say what the future has in store for anyone, but preparing in advance for a potential loss in income could help ensure financial stability. Before preparing for the future, it's important to assess current finances.

The first step is determining a budget. Take a complete accounting of current income, current expenses, and debt.

- \* Include all income sources, including child support and disability payments.
- \* Take into account all expenses, including gifts, meals out, and even lottery tickets if purchased regularly.
- \* Evaluate your debt, including secured debt payments like a mortgage or car payment, and unsecured debt payments like medical bills and credit cards.



This accounting will provide a good idea of where money is going each month and will help determine if there's a budget shortfall.

Once current income and expenses are determined, the next step is examining how money is being spent each month and if there are areas where you could cut back. Ask yourself what expenses would need to be eliminated if you had to live on a reduced income.

## Planning for Emergencies

If it is likely that your income will be reduced in the future, start cutting expenses now and put the money aside to build up an emergency fund. This emergency fund will help when an unexpected expense comes up, like car or home repairs or medical bills. Set aside \$50 a month and in 12 months you will have saved \$600, which could provide some cushion for unexpected expenses.

When anticipating an income reduction down the road, it's important to eliminate and stop accumulating unsecured debt. You can get details about your debts by requesting a credit report. Everyone is entitled to three free credit reports annually (one from each credit bureau). However, it's important to get these reports from [www.annualcreditreport.com](http://www.annualcreditreport.com). Here, the report will be provided for free and there will be no offers for a credit monitoring service, which charges a monthly fee. Once you have verified your debt, the next step is coming up with a plan to pay it off.

## Dealing with Debt

There are several options for dealing with unsecured debt. If you are current on payments, keep paying and try to pay extra each month to get out of debt faster. Anyone who is running behind should contact the creditor and explain the situation. In some cases, the creditor will work with customers to get payments back on track. If the credit card debt is too much to handle alone, consider professional financial counseling.

The National Foundation for Credit Counseling provides a directory of reputable, non-profit credit counseling agencies that help consumers figure out their options for dealing with debt. If appropriate, the counselor may recommend a debt management plan (DMP) to help pay off unsecured debt. The DMP, offered through a credit counseling agency, will set a five-year schedule of monthly payments to pay off the debt. Before signing you up for a DMP, a counselor will first do a budget analysis and provide an action plan, which will detail specific money management suggestions.

CONTINUED ON PAGE 7... | TOP |

CONTINUED FROM PAGE 6...

### **Be Cautious with Medical Credit Cards**

Recently, several large banks began issuing medical credit cards to pay for procedures that are not usually covered by insurance. Companies market the cards to doctors and other health care professionals as another payment option. However, these cards are coming under scrutiny by patient advocates. According to critics, some people are led to believe they are signing up for a payment plan with their provider. In some cases, the potential impact on credit history and score is not even discussed. Full disclosure might lead people to reject this option if they knew they were signing up for a credit card with possible interest, fees, and penalties.

It's important to understand all options when dealing with debt and educate yourself to make an informed financial decision.

Heather Murray is Manager of Education and Resource Development for Advantage Credit Counseling Service (dba Consumer Credit Counseling Service). For more information, visit [www.advantageccs.org](http://www.advantageccs.org).

## Medical Briefs

### **Acetaminophen Panel Offers Recommendations**

The FDA convened a two-day joint panel in May of pediatric and nonprescription drugs advisory committees. The joint advisory panel recommended that the FDA consider:

- \* standardizing all solid single-ingredient oral acetaminophen pediatric products to a single concentration, and
- \* expanding the dosing information for acetaminophen to children as young as 6 months.

The industry recently moved voluntarily to a single liquid concentration for children's products up to age 12 but does not believe a standard solid concentration is needed (1 'OTC Industry Standardizes Pediatric Liquid Acetaminophen Concentration,' *The Tan Sheet* May 9, 2011).

The committees also recommended weight-based dosing information, which is considered more accurate, in addition to the age-based guidelines currently on labels. (2 'Acetaminophen Panel To Mull Expanded Dosing, Standard Solid Concentration,' *The Tan Sheet* May 16, 2011).

## Resources

- \* **Annual Credit Report**  
[www.annualcreditreport.com](http://www.annualcreditreport.com)
- \* **Consumer Credit Counseling Service**  
[www.cccsstl.org/](http://www.cccsstl.org/), 888-656-2227
- \* **American Debt Counseling**  
[www.americandebt counseling.org/](http://www.americandebt counseling.org/)  
888-DEBT-USA (888-332-8872)
- \* **National Foundation for Credit Counseling**  
[www.nfcc.com](http://www.nfcc.com)
- \* **Federal Trade Commission, Bureau of Consumer Protection**  
[www.ftc.gov/bcp/index.html](http://www.ftc.gov/bcp/index.html)

Finally, the panel agreed that labeling for children under 2 years should include fever-reducing claims, but they could not agree to include any analgesic claims.

The Consumer Healthcare Products Association "strongly urges the FDA to include relief of pain as an indication on the OTC label," because acetaminophen is "a mainstay for the treatment of pain in children under 2 years."

### **Complementary and Alternative Therapy News**

Because chronic pain can be resistant to many medical treatments, people with chronic pain often turn to Complementary and Alternative Medicine (CAM) for relief. For fibromyalgia pain in particular, people try acupuncture, massage, tai chi, dietary supplements, and other approaches.

The National Center for Complementary and Alternative Medicine (NCCAM) at the National Institutes of Health has developed the NCCAM Clinical Digest to provide evidence-based information on CAM, including scientific literature searches, summaries of NCCAM-funded research, and fact sheets.

You can subscribe to the NCCAM Clinical Digest at <http://nccam.nih.gov/health/providers/digest/>.

| TOP |



# Economic Casualties of War

by Jani Larsen

Injured soldiers are coming home to the United States alive, more often today than during any of the past wars. That is the good news.

But 185,000 injured soldiers who served in Iraq and Afghanistan need treatment, help with recovery, and re-training, which will cost billions of dollars. This number is predicted to jump to 700,000 injured soldiers by the time the war ends.

According to the Department of Veterans Administration, nearly half of U.S. soldiers who were involved with the Afghanistan and Gulf wars are being treated for complaints of pain.

When predicting the cost of this war, the U.S. government projected a short duration and relatively few injuries, and was not prepared for how long and deep this war would go. The military is assigning longer tours, allowing less time for recovery, and rushing new troops to the front lines with abbreviated training, resulting in more injuries.

## A Larger Price to Pay

Post-Traumatic Stress Disorder is the leading cause of homelessness in veterans today. Traumatic brain injuries are topping out at 180,000 troops reported and a predicted 320,000 in total. When adjusting to a new life with pain and injuries, a lifestyle that was not expected or planned, these troops must wonder if they've truly come home. An alarming number of soldiers have not left the battle ground. In their nightmares and daydreams they can still feel, see, and hear the unmentionable, profound, and life-changing events that occurred right in front of them.

Unable to earn a living or relate to others, they are now losing their homes and families. They have already lost the life they once knew.

Now, veterans are fighting to get coverage for better treatment. The president has requested money out of the 2012 budget for this ever-expanding population to get the compensation they were promised.

Moreover, they may never get the compensation they deserve.

## Supporting Veterans

Many non-profits are willing to assist veterans with shelter, food, and clothing. There are a few independent contractors who adapt houses to the special needs of veterans. (T.J. Cantwell, of Rebuilding Together is one of them: [www.rebuildingtogether.org/](http://www.rebuildingtogether.org/))

Despite this help, veterans pay tens of thousands of dollars for medical specialists outside the VA system, pay for travel and shelter during hospital visits, and pay more to adapt their homes and cars to their new disabilities.

However, with the national deficit, recession, and unemployment rate, many civilians are finding it tough to stay ahead. Disabled veterans are living on a fixed income, dealing with stress, anxiety, physical, and mental issues. Was this their dream when they decided to fight valiantly for our nation against terrorism?

Penney Cowan, founder of the ACPA, developed Veterans in Pain (VIP) to help veterans learn how to live with chronic pain. It is just one small thing one organization is doing to make a huge impact on our nations' most prized resource.

What can you do? Start your research to search for and support organizations that assist veterans. Even one person can do so much for the veterans who sacrificed their health and lives for us.

Donate to the VIP Program by going to [www.causes.com/causes/572744#](http://www.causes.com/causes/572744#)

| TOP |



# Insomnia and Chronic Pain in Adolescents

by Tonya Palermo, PhD, University of Washington School of Medicine

Sleep difficulties are very common in individuals with chronic pain, occurring in children, adolescents, and adults across the life span (Roth-Isigkeit, Thyen et al. 2005; Tang, Wright et al. 2007). Most of these sleep complaints are about difficulties falling asleep, waking up during the night or too early in the morning, and feeling excessively sleepy during the day. These types of complaints are consistent with definitions of insomnia.

Problems with sleep are not benign. There are far-reaching adverse effects of inadequate sleep and untreated sleep disorders on health, mood, and cognitive and physical performance. In individuals with chronic pain, the combined effects of pain and poor sleep further diminish overall quality of life (Palermo and Kiska 2005). Importantly, research has also demonstrated connections between pain and sleep such that insufficient sleep can increase pain sensitivity, meaning that individuals who are sleep deprived may experience pain at higher levels.

## Identifying Sleep Problems

We were interested in understanding insomnia symptoms in adolescents with chronic pain in order to guide our future efforts at developing interventions that may address sleep problems. Adolescence is a particularly important time during which to consider sleep problems because many changes are already occurring in the sleep-wake cycle associated with advancing puberty.

In this study published in *Pain* in 2011 (Palermo, Wilson et al. 2011), we examined sleep quality, insomnia symptoms, and several possible behavioral and psychosocial predictors of sleep problems (pain, depression, and arousal at bedtime) in 59 adolescents with chronic pain and 56 otherwise healthy adolescents, ages 12 to 18 years.

Our findings demonstrated that over half of the cohort of adolescents with chronic pain (54.2 percent) reported insomnia symptoms compared to 19.6 percent of healthy adolescents. In addition, adolescents with chronic pain reported poorer sleep quality and higher levels of cognitive and somatic arousal at bedtime compared to their healthy peers.

## Causes of Poor Sleep Quality

There were several factors that predicted having insomnia symptoms including having chronic pain and higher levels of cognitive arousal (e.g., racing thoughts, worry, anxiety) at bedtime. Interestingly, severity of pain did not predict insomnia. These findings suggested to us that although pain may initially interfere with sleep, over time, it is likely that other behavioral factors play a role in the persistence of the sleep problem.

Given the magnitude of the problem with sleep and the potential negative consequences of insomnia on adolescents'



ability to cope with chronic pain, sleep should be an important priority in the care plan of those with chronic pain.

Additional research is needed to further guide assessment and treatment efforts with individuals with chronic pain; however, sleep should be evaluated in all individuals with chronic pain. Insomnia is a modifiable problem; current recommendations by the American Academy of Sleep Medicine (AASM) advise the use of cognitive-behavioral therapy instead of sleep medications for treatment of adult insomnia.

Cognitive-behavioral therapy has already been used effectively in adults with chronic pain and insomnia. Studies have shown that not only do insomnia symptoms improve but that pain is also reduced in individuals receiving cognitive-behavioral insomnia treatment (Vitiello, Rybarczyk et al. 2009). Sleep intervention may have substantial benefits for individuals with chronic pain.

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# ACPA Updates

Welcome to our new groups and facilitators.

**Art and Maureen Honegger**  
(Family Group)  
Antioch, CA

**Megan Lini**  
San Diego, CA

**Christal Ballard**  
Jacksonville, FL

**Cindy Ann Burgener**  
Green Castle, PA

**Thomas R. Potter**  
Harrisburg, PA

**Janet L. Ruddock**  
Alexandria, VA

**Tammy Teer**  
Richmond, VA



## Do You Use the Arts to Manage Pain?

A new ACPA project, The Art of Pain Management, will show how people with pain can use the creative arts in their pain management regimen.

Meredith Snow, M.S., ATR-BC, LCAT, is a board-certified art therapist and teacher, currently working at Stanford Hospital and Clinics in California in their Art for Health program. She has agreed to work with Penney Cowan, executive director of the ACPA, to develop a manual about how to use art as a creative outlet to cope with pain.

“We are always looking to expand the range of techniques that people can use to manage their pain,” said Penney. “Using the creative expression of art is a wonderful distraction from pain with which you can also release the emotions, create something beautiful, and expand your horizons.”

Meredith and Penney would like to include testimonials from people who have used painting, music, photography, dance, poetry or prose, singing, sculpture, collage, or even the culinary and horticultural arts as part of pain management. Send your story and contact information to **The ACPA, PO Box 850, Rocklin, CA 95677** or fax **916-632-3208** or email: **ACPA@pacbell.net**. Put “Art of Pain Management” on the envelope or in the subject line.

“As an art facilitator, I’ve helped people create imagery that expresses how they feel, forming a connection between the emotions of pain and a visual representation. They often can’t share this any other way,” said Meredith. “This helps to combat the depression that can accompany chronic pain.”

Learning a new task, like watercolor painting, also forges new neural pathways in the brain, she explained. “These are like exercises to develop the elasticity of the brain that may be neglected if your activities have been restricted by pain,” she said.

## International Integrative Medicine Day Spreads Awareness

International Integrative Medicine Day, January 23, 2012, has been established to inspire worldwide dialog, education, collaboration, research initiatives, and programming about integrative medicine. Integrative medicine is healthcare that is patient-centered, holistic, economically and environmentally sustainable, and conscious of integrating different global medical systems.

To learn more, visit the IIM Day website at <http://sites.google.com/site/iimday123>.

## Donate through the Combined Federal Campaign (CFC)

If you work for the federal government and plan to donate to the CFC in Fall 2011, you can designate your CFC gift to the ACPA. Just enter our name and code—10549—on your form. Your support will help many people.

## Know Your Dose of Acetaminophen

The ACPA is participating in the Know Your Dose campaign on the appropriate use of medications that contain acetaminophen.

Acetaminophen is found in more than 600 different prescription and over-the-counter medicines, including pain relievers, fever reducers, and sleep aids as well as cough, cold, and allergy medicines. On prescription labels, acetaminophen is sometimes listed as “APAP,” “acetam,” or other shortened versions of the word.

When used as directed, acetaminophen is safe and effective, but there is a limit to how much you can take in one day. An overdose of acetaminophen can lead to liver damage.

Follow the labels of your medicines and never take two that contain acetaminophen at the same time. Visit [www.knowyourdose.org](http://www.knowyourdose.org) to view a list of common medicines that contain acetaminophen, label reading tips, and more.

# Wherever Two or More are Gathered

by Janet Ruddock, facilitator, Alexandria, Virginia region

*It only takes two people to start a chronic pain support group.*

*My new group began at a local department store when I heard a friendly male voice behind me say, "I've been told about women with red hair."*

*Taken totally off guard, I swung around to encounter an older gentleman impeccably turned out with an engaging twinkle in his eyes. I don't generally engage in conversation with complete strangers, however, his good humor was contagious. I replied, "Only good things I hope!"*

*"Oh yes," he continued, "Only the best. Please take this as a compliment." I was warmed by his words. We went in separate directions, but as I continued shopping, I saw him again in the shoe department.*

*"How is it," he asked pleasantly, "that men come into a store, accomplish their errand, and promptly leave? You are barely halfway through the store and still going strong."*

*I responded, "Women browse their way through a store. I have problem feet and need to return yet another pair of shoes. Here I am in the shoe department. I merely took the scenic route."*

*"I have problem feet too!" he exclaimed. "It seems like they are on fire all the time. At night I stick them out of the covers. I try to explain this burning feeling to my doctors but maybe I don't describe it properly."*

*They call it neuropathic pain. I believe my medical internist and podiatrist are doing their best but nothing seems to stop the burning. I feel as if no one quite understands the pain I feel day and night." His obvious yet controlled frustration felt almost palpable. I so wanted to reach out to him.*

*"I understand perfectly" I assured him. "I have generalized neuropathic pain. The burning sensation exists at varying degrees daily throughout my entire*

*body. At times even a breeze triggers a "zinger" as if I had stuck my finger into an electric socket unleashing a static charge. Sheets rubbing on my legs can keep me awake half the night."*

*He responded with compassion for me but a sense of relief. "I can't tell you how reassuring it is to find someone who truly understands this problem. Sometimes I just feel so alone. Your symptoms sound far more severe and you have my greatest sympathy. How ever do you cope? I can just manage my painful feet. You look so put together and good natured."*

*My friend too looked and acted in every way a perfectly carefree individual. To the casual observer we appeared two healthy and happy people. In fact, he suppressed a painful limp and my legs burned from standing still too long.*

*Pain is often invisible. This can present difficulties for a person with chronic pain. If you don't appear to be in pain, other people, including the occasional doctor, have difficulty acknowledging the extent of your pain.*

*Fifteen years of experience with a number of chronic pain conditions has taught me to deal with the good days as well as the bad. Fortunately over time, through trial and error, various doctors have developed an optimal treatment plan of pain management for me. Chronic pain is not going away. You need to live with it as best you can.*

*My new friend reacted to my "Chronic Pain 101" speech with enthusiasm, clearly pleased to encounter someone who could relate to his problem and exhibit such a positive outlook. We plan to meet again soon.*

*Initiating a chronic pain support group can seem a daunting task. However, as long as people like this gentleman struggle alone with their pain, the need for peer support exists. My friend and I have no way of knowing where our first meeting in the mall may lead. Our twosome may not appear to be a "group" at all, but it's a start.*

# Book Review

## *The Will to Walk: Journey of Recovery from Paralysis*

by Marjorie B. Holcombe

Review by Tara White, RN

The author of this book, Marjorie B. Holcombe, states that this book was written to help others, and that is just what it will do.

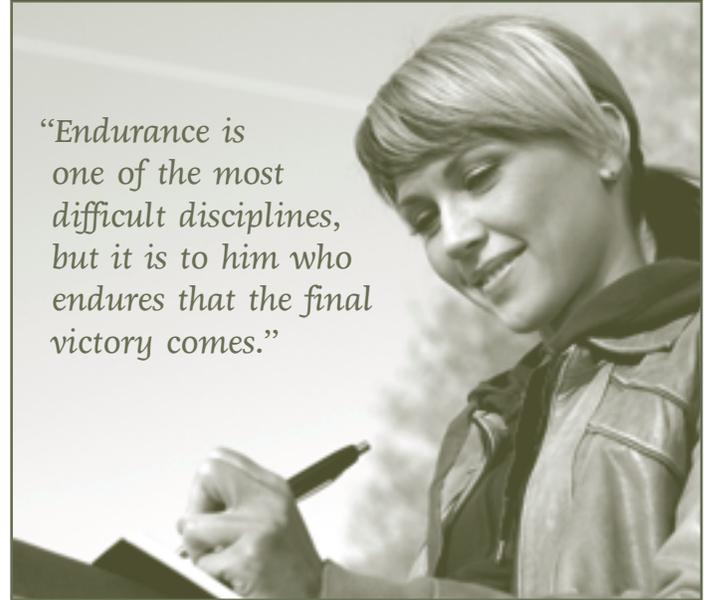
She is suffering from paralysis due to a severe case of transverse myelitis (inflammation of the spine), but anyone with a physical disability who is determined to find a better life will be inspired by this book. Marjorie Holcombe displays incredible courage in her struggle to regain her ability to walk and once again enjoy an active, outdoor life.

After a diagnosis of cancer, she suffers terrible burns from radiation, and then is mistakenly given toxic levels of chemotherapy causing temporary hearing loss, paralysis of her legs, and severe weakening of her arms. She is then treated with massive doses of steroids that cause their own severe side effects. Lesions along her spine prevent her muscles from receiving messages from her nerves. Despite physical, occupational, and exercise therapies, Ms. Holcombe realizes very little progress, and is told it could take years to recover, if she ever does.

Absolutely determined to walk again, the author seeks out alternative treatments. During a treatment of Chinese scalp acupuncture, she is told that by exercising her muscles 6 to 10 hours a day, she can regain the use of her legs. Depleting her savings, she hires a personal assistant and personal trainer and begins the recommended rigorous program. Her devoted life partner designs equipment and restructures their whole home to accommodate a hospital bed, then wheelchair, plus live-in help.

Emerging out of the chaos of early treatment, final diagnosis, and devastating prognosis, through the “fog of confusion” of treatments and questions, she never loses her determination. Despite setbacks, she maintains steady progress. However, she also begins a life of chronic pain from reawakened nerve fibers and muscle spasms. Realizing that anger is a “useless waste of energy,” she also knows that asking “why me” would only take away from the “all-consuming task of surviving.”

She describes it in a way we can all learn from: “Whereas once I had aggressively attacked my days with zestful purpose, during the months of recovery I eased more and more into



*“Endurance is one of the most difficult disciplines, but it is to him who endures that the final victory comes.”*

inner stillness, sometimes feeling comfortable and natural in it, much as one might feel sitting satisfied in a warm sunny field of wild flowers. Energetic people often seemed so engaged in their personal dramas as to be unaware of this other side of life, of the quiet witnessing that invites another aspect of our soul to emerge. Such quietness, an absorbing sinking into a newly emerging reality of self, becomes the rich soil for inner transformations at a very deep level, a level beyond the busy, aggressive, purposeful rational mind.”

She kept her life simple and limited her involvements. Distaining the label of courageous because it implied facing fear, she learned instead to accept present realities, “that one’s attitude toward situations determines the nature of the experience.” Included at the end of the book is her own exercise program and many resources she utilized throughout her long road to recovery.

I was very impressed with the author’s perseverance despite her poor prognosis. Most people would feel just bitter acceptance. However, Ms. Holcombe dug deep inside herself “to develop new strengths, gain new understanding.” She believed wholeheartedly in the Buddhist teaching: “Endurance is one of the most difficult disciplines, but it is to him who endures that the final victory comes.” She does indeed earn this final victory and is truly a very inspirational woman.

*The Will to Walk: Journey of Recovery from Paralysis; author, Marjorie B. Holcombe; Precious Sounds, 207 Pages, \$18.55 ISBN 978-0-615-36264-9, [www.thewilltowalk.com](http://www.thewilltowalk.com)*

# Members' Forum

## An Essay to Mr. Pain

From time to time we share essays written by facilitators and members of ACPA and of our support groups. Members of the Nevada County ACPA support group wrote letters to "Mr. Pain" to describe their everyday battles and successes.

Mr. Pain,

A year ago, you were winning. You were who I was. My days and nights were measured by your intensity. I spent an amazing amount of time and money trying to get rid of you. You overwhelmed me. You affected every area of my life. My daily activities were halted, my relationships hindered, and a feeling of sadness and hopelessness settled over me. My world shrunk. Staying home was the easiest thing to do. My life as I knew it was taken from me. But, you didn't win!

It seems there was always the faintest glimmer of hope within me. That little spark was fanned into flame and I won! I'm back—the me I used to be, the real me. My family and friends hung in there with me and encouraged me; my faith lifted me up and I now know you will never win.

I say with the Scriptures, "The Lord is close to the brokenhearted and saves those who are crushed in spirit."

(Psalm 34:8) "He reached down from on high and took hold of me; he drew me out of deep waters, rescued me from my powerful enemy. The Lord was my support. He brought me out into a spacious place; he rescued me because he delighted in me." (Psalm 18:16-19)

**You lose, Pain!**  
— Marlyn Blount

## Some Nights Are Like That

by Carol Gieg

*It is three a.m. and I am wide awake. A familiar nausea taunts me. I have assiduously ignored its warning the last half hour or so before I lay down to sleep. I simply am not going to allow it to win this time. I am stronger than that.*

*Dream-littered slumber masks the further warnings of advancing troops up the right side of my head. They attack as an enormous wave of pain, progressing rapidly upward over the occipital ridge. The wave gathers reinforcements—more nausea and tears.*

*Fortified, they march without pause, directly towards the gripping stronghold of Trapezius. The troops surround and press inward. Sweeping their guns skyward, they take aim and shoot. The shots ricochet throughout my head and lodge behind my eyes. Satisfied in their mission so far, they pause to reload.*

*Fully awake now, I am livid. I grab for my temples and squeeze shut my tearful eyes. True to form, I refuse to retreat and instead, dig in my heels. I shift my head from side to side, seeking respite long enough to plan my counterattack, and determined to defeat this evil force attacking my head. I plan to fortify my own soldiers with those weapons best-suited to defend my precious tender soil from the marauders.*

*But it is no use. Sleep is no longer anywhere near a possibility.*

*Pain advances again until, finally, I order a retreat, surrender, and grab for my medication.*

*My lads and lassies break out the litters and begin loading their wounded comrades, carrying them to medical attention. I am submerged again and again, leveled by shots of pain even as my own soldiers attempt to stitch and mend me. Opposing troops, as though to pour salt over the open wound of this overwhelming defeat, wave the flag of triumph emblazoned, "MIGRAINE."*

*I call in reinforcements, take another medication, sit up or stand, take a walk, try natural vinegar recipes, ice packs, caffeine, and succumbing to nausea. Soon, all been spent. Now I can rest while my troops hold MIGRAINE at bay.*

*But I know the pain army will be back, once I recover enough to fight again. As soon as I am caught unawares—too fatigued, too hormonal, too traumatized, too allergic, too emotionally-stressed, or too something I don't know about yet—then will the troops gather; then will the wave swell; then will the attacks commence.*

Some nights are like that.

| TOP |

## 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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Thanks to these corporations for grants that enables ACPA to fund special projects:

**Endo Pharmaceuticals:** For the Veterans In Pain (VIP) program. Supporting ten presentations on pain management, and peer-led groups in VA facilities, as well as a grant to film one of the presentations

**Medtronic Foundation:** Two-year grant for the Growing Pains Interactive Module

**Millennium Laboratories:** For a Pain Week 2011 exhibit opportunity

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.

## Tributes

IN HONOR OF  
ARIELLE GORELICK  
ON HER GRADUATION

Given by The Shovers Family

IN MEMORY OF  
JEFFREY CARL REINKING, MD  
SURVIVING SPOUSE

MRS. ROBIN REINKING

Given by Louis Kaufman

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