



# CHRONICLE



## Family Matters

by Penney Cowan, Executive Director, ACPA

### INSIDE

- 2 [Caring for Caregivers](#)
- 5 [Caregivers Rights and Resources](#)
- 8 [Defining Solutions for Workers' Comp](#)
- 10 [Pain Researchers Team Up](#)
- 11 [ACPA Update](#)
- 12 [Fibro Survey Reveals Perceptions](#)
- 13 [Veterans in Pain](#)
- 14 [Tributes](#)

### TWO TAKES ON FIBRO:

New survey reveals surprising differences between public perceptions and private realities...[page 12](#)



Join Us on [Facebook](#)

*"I know that I am responsible for the pain my mother has. When I was a little girl, I put my arms around my mother to hug her and did something to her neck. Ever since that day, she has been in pain. It is my fault that my mother hurts all the time."*

**B**elieve it or not, the first time the ACPA held a family group meeting, a ten-year old girl told that story. She continued, "I do everything around the house. I come home right after school and clean the house. Then I make dinner for the family. My mother cannot do much or her neck hurts. My friends have difficulty understanding why I don't have time to be with them. But then, their mom doesn't have chronic pain. They don't understand. I would like to talk with kids that do understand." My heart broke as I listened to her words. What a terrible life for that child!

#### **When Pain Invades a Family**

Chronic pain is a family matter. We need to be aware that chronic pain is not just about the person with pain, but affects every member of the family, including the children. The person with pain, for many reasons, can take center

stage in a family. But if pain issues consume the family, the other needs of the family will never be met.

We have heard many

stories about couples who have been working all their lives and saving for retirement.

Then one of them develops a chronic pain condition that requires expensive medical treatment, tests, and therapies. They watch their life savings vanish, making it impossible for the well spouse to retire as planned. If they are already retired, they can face financial ruin.

We can imagine that anyone who had two full-time jobs would be exhausted all the time. But that is what it is like when chronic pain invades a family. The well spouse does his or her job, but also, in many cases, comes home and takes care of the spouse with pain, the house, and family. That is exhausting both physically and emotionally. It can wear you down to the breaking point.

As with chronic pain, it is what we cannot see that is the most painful. On the outside, the well spouse may look fine to friends, coworkers, and family. What they cannot see is the emotional and financial struggles that must be dealt with every day.

CONTINUED ON PAGE 7...

# Caring for Our Family Caregivers

by Erin Kelly

When pain affects someone you love, it's natural to want to help as much as you can. But when pain goes from a short-term crisis to a long-term part of life, it's important to develop a sustainable caregiver relationship—one that lets both partners support each other and maintain balance.

Handling chronic pain as a team requires good communication skills, creativity, flexibility, and a good deal of patience. "It's very difficult to make plans," says John Hammond of Quincy, Massachusetts, whose wife Connie lives with chronic pain. "You're often reacting to whatever the situation is. The pain is always there, but some days are better than others," Hammond says.

Ron Dallas of Arlington, Massachusetts, who is a caregiver for his wife Janice, agrees. "Patience is the biggest thing you have to learn," he says. "You have to be flexible, because your plans can change at the last minute. Yesterday you might have made a plan to do something but today it's just not going to work."

And a good caregiver has to trust that changing the plan is the right thing to do. "It's so important that the people close to you really listen to you, believe you, and don't question your description of the pain or your limitations," points out Cindy Steinberg. She is an ACPA regional director who facilitates a support group in Arlington that Hammond's and Dallas's spouses have attended. "It's critical for partners, spouses, and family members to believe that the pain is what you say it is."

When your caregiver is a spouse or partner, the day-to-day tasks of your life together have to be rearranged to accommodate changed abilities. "A lot of people with pain are used to being very productive—the kind of super-person who cleans the house, and works at a job, and gets the kids ready for activities," Steinberg says. When pain makes those things impossible, it can be difficult for the family to accept. "They think, 'you were home all day, couldn't you just have done the dishes?' They don't understand that small tasks can be very difficult for someone living with chronic pain," she explains.

Solving this problem requires communication. Partners need to discuss which tasks are difficult, brainstorm ways to make them easier, and come to an agreement about what to expect. Steinberg says, "You might need to take on different roles. For example, one person takes over doing all the laundry and errands and the other person handles paying the bills, or arranging family members' activities, or home repairs." All jobs are important, she says, adding, "Each person needs to feel they are contributing."

## Adapting Tasks to Abilities

ACPA facilitator Henry Ilsley has become an expert by trial and error on adapting household tasks to the abilities of the family. He has lived both sides of the caregiver equation. His wife Elna uses a scooter, brace, and a cane because of paralysis. He helped her stay active until his chronic spinal pain from an earlier motorcycle accident became disabling. "We're mutual caregivers now," he says. "We figure between the two of us we make up a good 2/3 of a person!"

Since both the Ilsleys have physical challenges, they've turned to technology to help with some tasks. "Neither of us can run a vacuum, but we have a Roomba—it vacuums the house by itself and all you have to do is empty the dust bin," Ilsley says. Winter brings extra burdens in their Bradford, Vermont home. "I can't shovel snow but I have a lawn mower with a snow blower and plow attachment that scrapes the walk. There are so many things out there to help you, if you can find a way to afford them."

Together they find low-tech ways to make things easier. Ilsley says, "one of the coping skills is learning to do your own occupational therapy. I can't carry grocery bags in my arms, but I can hug them tight to my chest," he says, noting that

[CONTINUED ON PAGE 3...](#) | [TOP](#) |



# Patience is the biggest thing you have to learn.

CONTINUED FROM PAGE 2...

his wife usually takes charge of long shopping trips after his energy wanes. “We have a ramp and we use a wagon to get things to the house.”

In the Dallas household, “Janice does a lot of shopping by Internet, for clothes and household items,” says Ron Dallas. Although they sometimes pay extra for shipping, he says the reduced stress makes it worthwhile. “With clothes, you can’t tell what something will look like so you end up buying more and returning some—but it means she can go shopping by herself, on her own time. It’s worth it.”

And how or when things get done is usually not as important as some people might think. “Sometimes your caregiver doesn’t do a task in the way or at the level you would have done it yourself,” says Steinberg. “You need to be flexible, relax your high standards, and keep a positive attitude. Appreciate the help given to you. Eighty percent of the job is better than none at all!”

Part of the compromise between a person with pain and a caregiver includes negotiating how much the caregiver should do. “The caregiver might want to do everything they can to be helpful, but it’s important to not do so much that the person with pain feels helpless,” Steinberg says.

## **Providing Emotional Care**

Ilsley knows that he can’t always help his wife physically—but he can provide other types of support. Sometimes he can see that she is in a painful situation and stress is making it worse. He is able to help her focus and become calmer. “I say, ‘Just stop, wait, and tell me what you need. If I can’t do it, then we’ll wait,’” he explains.

Connie Hammond appreciates getting this same kind of emotional support from her husband John. “Most important to me is the fact that he just lets me vent when I need to,” Connie says. “It’s okay to be angry and express your feelings, and it’s important for John to feel like he doesn’t always have to have a solution. It helps that he listens and is there with a hug.”

For Connie, sitting or standing for a period of time is difficult, so they team up to get everyday tasks accomplished. “He lets me try what I need to try,” Connie says, “and he often does things on his own without me asking. It lets me know he’s not feeling an extra burden. I feel very blessed in that regard.”

The Hammonds met before Connie’s pain problems started, but their long-distance romance didn’t lead to marriage until after she had begun living with chronic pain. “Actually I think that the fact that I didn’t run when she was in a wheelchair for a year might have helped her decision process,” John explains.

“She could see I was for real.” Connie was able to walk down the aisle at their wedding in 2005.

## **Supporting a Relationship**

It’s also important to plan activities and maintain your relationships, whether it’s with a caregiving spouse or a close friend. “Set some small goals together—for example, take a nice walk,” Steinberg says. “Maybe you can’t go for a run or go skiing together, but you will enjoy a walk. And perhaps you can build up to a bigger goal.”

John Hammond plans activities they can do on short notice when those good days come. “We try to keep opportunities in mind—a movie or other places we can go for a day trip if she’s having a good day,” Hammond says.

Steinberg and her partner have adapted their hobbies to fit her abilities. “My husband and I love to go to concerts, but I can’t sit upright that long,” she says. “We figured out that if I take a break at intermission and find a place to lie down for 25 minutes, then I can go back and we enjoy the rest of the concert.”

Even fun activities require flexibility and good communications. Hammond was reminded of that last summer when he and Connie planned to take a day trip to Rockport. “We’ve been there before and enjoyed it,” he says. Although she had initially been feeling well, Connie struggled preparing to leave, and John realized it was becoming painful and stressful for her. “I think she was doing it for me because she thought I wanted to go. I was doing it for her because I thought it would be a nice day out,” Hammond says. “We realized that we had to be more careful,” he admits.

During any long-term relationship it’s likely that both partners will be caregivers for each other now and then. “Nobody gets through life without problems,” says Steinberg. “At some point the person with pain is going to be the support for her or his spouse.” Dallas is a caregiver for his wife now, but notes that she cared for his mother for several years. Sharing those experiences can help strengthen a caregiving relationship.

## **Taking Time for Yourself**

Caregivers have to find time for themselves too. When Ilsley worked as a nursing assistant in a geriatric psychiatric center, he persuaded colleagues to take two-week vacations because one week wasn’t enough time to let go of caregiving stresses. “Often people taking care of you won’t admit that they need time for themselves,” he says. “But the truth is, they’ll provide for you better if they have time off when they can breathe their own air.”

CONTINUED ON PAGE 4... | TOP |

## Caring for Our Family Caregivers

CONTINUED FROM PAGE 3...



Members of the Arlington, Massachusetts ACPA support group are encouraged by Cindy Steinberg (front).

*Empathy can help avoid problems.*

Ilsley says he's still learning how to support his wife's need for alone time. "My wife is a giving person and sometimes she won't admit it when she wants to do something without me," he says. "I like my wife to be with me whatever I'm doing, but sometimes she wants to be off by herself doing a crossword puzzle." He says that he's making an effort to learn what she enjoys—mainly by observing, hypothesizing, and testing his theories over time.

Hammond tries to balance supporting his wife and maintaining his personal interests. "I want to take care of the person I love, but I'm aware that I need to do things for myself as well," he says. "I also try to encourage Connie to do things she enjoys when she can."

"I do have a sense of guilt, because I like hiking and other outdoor activities," says Hammond, who first met his wife at a fitness convention years before her medical issues started. "I'm aware that my participation in such activities can just act as a reminder for Connie of the things she used to enjoy with me," he says, "particularly when she's back home struggling through a day with little sleep and pain that leaves her feeling like she's been beaten with a baseball bat."

But Hammond's wife is also empathetic. "Connie feels guilty as well sometimes," Hammond points out. "She feels that she's holding us back."

### **Empathy Requires Communication**

A caregiver's sense of empathy can help avoid problems if someone with pain does too much. "They can get tired and overwhelmed," says Dallas, explaining that fatigue and pain can lead to poor decisions. "If you're aware of the circumstances you can help catch that before it happens," he says.

How you phrase things makes a difference. If you're bringing up something your spouse might not want to hear, Ilsley says, "you have to be careful about how you say it. Instead of making an 'ending' statement like, 'You're this way,' try asking a question, like 'Do you think you might have changed how

you are doing this task?' or 'Do you hurt when you do that this way?'" He points out that questions are less likely to spark denial. Questions also affirm that the person with pain is competent to investigate the issue.

Hammond adds that picking the right moment to start a discussion is also key. "When she's having a bad day or a bad week, that's not the best time to bring up emotional issues," he says.

### **Preparing Caregivers to Help**

Ilsley would like to develop a crew of additional caregivers, volunteers who go through the kind of education that ACPA offers for family members. They could provide a break for regular caregivers or assist people who don't have a close friend or spouse able to help. "The ACPA family workbook really gives a good perspective on the kinds of situations you're likely to face as a caregiver," Ilsley says.

Ilsley says that sometimes people can be so distracted by pain that they tend to lash out at their caregivers. "It's a 'fight or flight' reaction. It's not that they're angry at you or dislike help, but they can't deal with the situation," he says. "They can't leave, so they look for another way to protect themselves."

A fresh caregiver can help break a cycle of bad behavior. "When you interact with a regular caregiver you can stop using self-control," Ilsley says. "You think you're privileged because they love you and they have to put up with you. When somebody from outside the situation comes in, you start to be aware of your actions."

### **Supporting Other Caregivers**

Caregivers are welcome at most ACPA group meetings, and several of the caregivers interviewed in this article have benefited from being involved. Steinberg says, "It seems like the people who bring a support person with them—even if it's just for the first few meetings they attend—do have great success in finding enjoyment in life despite their pain."

CONTINUED ON PAGE 13... | TOP |



# Rights and Resources for Family Caregivers

by Alison Conte, Editor, The Chronicle

Chronic pain affects not only the persons with pain, but also those around them. Close friends and family often share the consuming and controlling aspects of chronic pain, everything except the pain itself.

Initially, family members go through the confusion of trying to understand your pain and the new limitations on your abilities. They may take on new roles, picking up chores that you can no longer accomplish, or being the sole bread-winner for the family. They may be overwhelmed by the bills and paperwork involved in ongoing medical treatment. They may also miss the socializing, travel, and hobbies that you enjoyed together, before pain reduced your activities.

Just as you feel you lost your old life, your spouse may feel like they've lost the person they married.

But your family travels with you on the journey from patient to person. As you learn to manage your pain and regain control of your life, you are asking your family to shift gears again. Just when they've accepted the role of caregiver and support person, routines change again, changes that can be disconcerting.

Returning home from a pain management center, one ACPA member was eager to use her new skills and get re-involved in life. Penney Cowan tells the story in *Staying Well*.



“My family still saw me as a ‘disabled’ person. There was a large gap between my need to be who I was and their need to protect me as a patient. I had worked very hard to become a person again and I was not going to let anything interfere. They were worried that I would have a few good days, hurt myself, and be back where I started.”

Although you have experienced personal growth and understanding, your family may not have. They may still see you as a patient—the person you used to be in constant pain. They can see that you have more physical stamina, but your feelings will remain hidden unless you express them.

Stating how you feel provides a clear picture of what you are experiencing. No one can read your mind. If you need support, a sympathetic ear, encouragement, or help, you must ask for it. On the other hand, when you want to extend your activity, and reassume a daily chore perhaps, you must let your family know that too.”<sup>1</sup>

Asking your caregivers for help can be particularly difficult when you have worked so hard to regain function. As described in *Staying Well*, “It was difficult to admit that there were things that were difficult to accomplish and asking for help reinforced my sense of weakness. I could not allow others to see me as weak and unable, so I struggled to accomplish things I felt I “should do.” Help was a negative word and one that made me feel weak.”

“We do not hesitate to ask for help with things that are “socially acceptable” such as putting up wallpaper or moving heavy objects. The difficulty comes in asking for help with the little everyday things that we used to do without exerting much effort. Asking our family for help is not weak. Give yourself credit for attempting to remain active and functional,” states *Staying Well*.

As with all relationships, relationships with your family and caregivers require lots of communication, understanding, patience, and persistence. You must also realize that having chronic pain doesn't give us the right to disregard another's feelings and needs. Our caregivers can't take the pain away, but we must respect their efforts to help improve our quality of life.

[CONTINUED ON PAGE 6...](#) | [TOP](#) |

## Rights and Resources for Family Caregivers

CONTINUED FROM PAGE 5...

### Caregiver Rights

Fifty million Americans care for loved ones with a chronic illness, disability, or the frailties of old age.

Caregivers walk a fine line in helping a person with pain. They carry their own burdens, but feel they cannot express their complaints, which seems so small compared to those of the person with chronic pain. Caregivers must recognize that they have rights, too.

As a caregiver, you have the right to:

1. **Take care of yourself.** Taking care of your own health will give you the ability to take better care of your friend or relative.
2. **Recognize the limits of your own strength and endurance.** Be open to technologies and ideas that help your loved one become more independent.
3. **Accept offers of help and suggest specific things that friends and relatives can do to help you,** such as providing food, taking your loved one to the doctor, or giving you some time off.
4. **Express your anger and frustration** when you have to, but watch out for signs of depression in yourself. Don't wait to get professional help if you need it.
5. **Do some things for yourself.** Maintain relationships and activities in your life that do not include the person you care for, just as you would do if they were healthy.
6. **Protect your individuality** and make a life for yourself that will sustain you when your care-giving role ends.
7. **Advocate for, seek out and use resources and support groups for caregivers.** <sup>2, 3</sup>

A new resource for caregivers, Caregiver Cornerstones, suggests there are four cornerstones for caregivers of people with chronic pain.

1. **Learning about pain management:** Become part of the treatment team.
2. **Caring for a person with pain:** Make sure they receive proper assessment and follow their treatment plans.
3. **Caring for yourself:** Being a family caregiver can be a demanding job. Allow others to help provide a support system.

4. **Advocating for all people in pain:** Help raise awareness about the importance of access to appropriate and effective pain care.

Caregiver Cornerstones suggests that caregivers:

- \* Believe your loved one's report of pain.
- \* Pay attention to the physical, emotional, and behavioral changes that indicate they might be in pain.
- \* Attend visits to the healthcare provider with your loved one and take notes during the visit.
- \* Use the ACPA pain logs to track pain episodes.
- \* Collect all personal information, diagnosis, and bills before you talk to an insurance company to get help with claims. Visit [www.thefamilycaregiver.org/pdfs/insurancetalk.pdf](http://www.thefamilycaregiver.org/pdfs/insurancetalk.pdf) for tips and guides.
- \* Follow treatment plans, including exercises and medications, precisely.
- \* Keep a record of all medications being taken (prescription and over-the-counter medications) on the ACPA med card.
- \* Practice medication safety through the suggestions at [www.theacpa.org/67/More%20About%20Medications.aspx](http://www.theacpa.org/67/More%20About%20Medications.aspx)

Caregiver Cornerstones, [www.partnersagainstpain.com](http://www.partnersagainstpain.com), is a partnership among the National Family Caregivers Association, <http://thefamilycaregiver.org/>, Partners Against Pain®, and author Lee Woodruff. Communication tools can be found on the ACPA website at [www.theacpa.org/25/CommunicationTools.aspx](http://www.theacpa.org/25/CommunicationTools.aspx)

- <sup>1</sup> **Staying Well: Advanced Pain Management for ACPA Members,** by Penney Cowan, Chapter 4.
- <sup>2</sup> **Excerpts from Caregiving: Helping an Aged Loved One** by Jo Home, Alzheimer Association.
- <sup>3</sup> Caregiver Cornerstones, <http://www.partnersagainstpain.com>

### Resources

The ACPA Family Manual can help family members manage lifestyle changes and difficulties due to living with a person with chronic pain and begin to rebuild a mutually supportive family unit. <http://acpa.stores.yahoo.net/acfamman.html>

Growing Pains is a support group for young people struggling to balance the obstacles of growing up with the challenges of chronic illness. Members communicate through email and snail mail. Contact the group at [growingpainsacpa@aol.com](mailto:growingpainsacpa@aol.com).

Well Spouse Foundation, [www.wellspouse.org/](http://www.wellspouse.org/), advocates for individuals caring for a chronically ill and/or disabled spouse/partner through peer to peer support and education.



CONTINUED FROM PAGE 6...

NFCA: National Family Caregivers Association at <http://thefamilycaregiver.org/>, empowering and supporting caregivers

The Johnson & Johnson Caregiver Initiative at [StrengthForCaring.com](http://StrengthForCaring.com) provides family caregivers with a broad range of expert content and information, an emerging on-line community, daily inspiration, and much needed support.

Family Caregivers Alliance, [www.caregiver.org/](http://www.caregiver.org/). Long recognized as a pioneer in health services, FCA now offers programs to support and sustain caregivers.

National Alliance for Caregiving (NAC) at [www.caregiving.org/](http://www.caregiving.org/), is a coalition of national organizations that conducts research and increase public awareness about caregivers and their responsibilities.

National Organization for Empowering Caregivers at [www.care-givers.com](http://www.care-givers.com) provides assistance, education, support, referrals, and respite volunteers as well as message boards, chat rooms, a list of online and off-line resources, and a newsletter.

### Books

*The Tough & Tender Caregiver, A Handbook for the Well Spouse*, by Dr. David Travland & Rhonda Travland, [www.caregiverburnout.org/](http://www.caregiverburnout.org/)

*Helping Yourself Help Others: A Book for Caregivers* by Rosalynn Carter, in which she discusses how caregiving provides personal growth, satisfaction, and greater insight into people. [www.amazon.com/Helping-Yourself-Help-Others-Caregivers/dp/0812925912](http://www.amazon.com/Helping-Yourself-Help-Others-Caregivers/dp/0812925912)

On the ACPA website, additional books for caregivers and families can be found under "Relationships" at [www.theacpa.org/59/Helpful%20Reading.aspx](http://www.theacpa.org/59/Helpful%20Reading.aspx)

## Family Matters

CONTINUED FROM PAGE 1...

### Sharing the Consequence of Pain

Family members may not have the physical pain, but otherwise, they are experiencing the same issues as the person with pain. They face depression, guilt, anger, self-doubt, confusion, and many more emotions brought on by living with a person with pain. Some cannot hold on and the relationship ends. Some try desperately to cope alone with this heavy toll. Others do not take time to even consider their own needs, much like the little girl at the family support group, and are controlled by the pain—even though they are not in pain.

Family matters for so many reasons. If we ignore their needs, the entire family will never heal and most likely will carry these scars the rest of their lives. We need to take the "I" out of illness and move toward the "we" in wellness.

In the book, *Helping Yourself Help Others* by Rosalynn Carter, the author talks about the Eight Ingredients of Caring.

- \* **Knowing:** Have a clear understanding of the person you are caring for.
- \* **Alternating Rhythms:** Give yourself time to look at the situation, making changes in the way that you provide care.
- \* **Patience:** Exhibit patience for both the "patient" and for yourself. Give time to the people with pain to do things for themselves when possible—even if the end result is not a perfect job.
- \* **Honesty:** Endeavor to see the person with pain as he or she is, not as you wish he or she would be. Understand whether your help is useful or harmful.
- \* **Trust:** Allow the person with pain to be the best he or she can be, even if it is not what we would like. Sometimes trust means that you must allow others to be part of the caregiving team, rather than believing that you are the only one who can be helpful to the person in pain.
- \* **Humility:** Admit that you do not have all the answers and that you must learn from your mistakes.
- \* **Hope:** Accept that your actions truly make a difference in the life of the person with pain. Know that you are appreciated.
- \* **Courage:** Accept all of the issues that are a part of chronic pain. Take one day at a time.

Know that you and your family can work together in your journey from patient to person. Others in caregiver support groups and ACPA support groups can help.

In this issue you will read some personal stories from people with pain about family healing, as well as information about caregiver support groups and resources. Each person has a part in achieving wellness. Remember, only by believing that WE are in this together can WE make a positive difference. | TOP |

| TOP |

# Ability and Motivation – Defining Solutions for Workers' Compensation

by David A. Hanscom, MD

It is well known that chronic pain can be a major factor in prohibiting people in the workers' compensation system from returning to their jobs. But often, it seems, the system itself is a barrier to recovery and return to work.

As a surgeon treating patients who've been injured on the job, I've been heavily involved in the issue of workers' compensation for over two decades. I have found that the workers' comp system is incredibly frustrating, making workers so angry that they lose their motivation to work through the system.

Workers' comp has been discussed extensively in the medical community for years, and it seems as if every possibility for improving the system has been covered. Many interventions do work on a small scale and numerous structured programs have had spectacular results. The problem is that too few people in workers' comp have access to the highest quality programs. We need to elevate workers' comp-related programs and systems nationwide to give individuals a greater chance to heal and return to work.

## A New Approach

Last year, I encountered a model of thinking that can be applied to the workers' comp issues in *Influencer: The Power to Change Anything* by Kerry Patterson, et al<sup>1</sup>. The authors propose that the only way to bring about a paradigm shift is to figure out the role that **ability and motivation** play in the situation that needs improvement. This is a terrific method for reorganizing our thinking regarding workers' comp treatment and policy.

## No Ability to Navigate Through the System

The average worker does not have the ability to navigate the workers' comp system. Among the obstacles are:

- \* Lack of standardization of reporting an injury with all of the involved parties
- \* Inability to quickly communicate with the claims examiners
- \* Too many parties involved: claims examiners, human resources, vocational counselors, physicians/chiropractors, and attorneys
- \* Lack of a specific care plan that includes the medical, personal, and employer issues.

In the present system, workers undergo too many treatments that have a low chance of success. They are given hope, which is then crushed. They fear the loss of their jobs and the resulting financial devastation. They fear the loss of their health, adding stress that can aggravate pain and inhibit recovery.

All of us need and want to be heard and most workers and their doctors are more than happy to engage in a mutual problem-solving process—if they can just get the right person on the phone. It goes without saying that the workers' comp process is infinitely more complicated than it needs to be—a serious weakness when a person's whole livelihood is on the line.

So in terms of ability, we have zero ability to successfully and easily navigate the workers' comp system.

## Motivation is Destroyed by Frustration

Losing control over your life can make you angry.

In the workers' comp system, injured workers have little or no say in their care and are not given sufficient structure or direction. They usually become increasingly angry as their care drags on without a goal or hope.

When people are angry, not only are they unable to see their situation clearly, they also want to lash out and destroy. Anger is like a land mine. The negative energy is directed inward, as well as outward. Distracted from the goal of trying to regain a full and healthy life, people instead set out to wreak havoc on the administrators who, in their eyes, are treating them badly. In this scenario, even the most well-intentioned efforts from people in the system are met with resistance.

In addition, anger can increase pain, destroy quality of life, and drain the energy needed for problem solving.

The situation directs the injured worker's **motivation** in exactly the opposite direction from that needed to regain a full and rich life. System-driven solutions are not going to negate a given worker's deep anger. It is devastating to all parties involved.

## Redefining Solutions—Ability

Solutions can be developed at three levels: personal, system, and social. Historically, changes that have improved a worker's ability to rehabilitate include:

- \* Light duty programs
- \* Nurse case managers
- \* Streamlined reporting of the injury
- \* Pre-determined care pathways set up with all parties
- \* Pain clinics
- \* Adjusting wages to allow gradual re-engagement in the workplace
- \* Work hardening programs of physical preparation for return to work
- \* Aggressive job modification





CONTINUED FROM PAGE 8...

However, there are few efforts directed towards the worker taking control of his or her own care. I would suggest developing education manuals in multiple languages that cover:

- \* Realistic expectations of the workers' comp system
- \* Resources specific to the employer and state
- \* Specific strategies to deal with obstacles
- \* Anger and anxiety management
- \* How to manage chronic pain (before the claim spirals out of control)

In addition, workers should be required to meet with a mental health professional if the claim is open more than a month. Plus, claims should be computerized to make treatment transparent and more interactive.

### **Change at the Societal Level**

Though societal attitudes towards disability are improving, many among the general public still do not believe a person's claim of severe, ongoing pain. Some suggestions for change at a societal level are:

- \* Education of the public about the degree of the problem. With 116 million people in chronic pain it may be our *most important* public health issue.
- \* Education regarding the severity of the impact that chronic pain has on quality of life.
- \* Better understanding of the effects of labeling.
- \* Connecting groups around the world who are committed to furthering the understanding and awareness of the Mind Body Syndrome. It is treatable with often dramatic results.
- \* Early detailed education in chronic pain for students in medical and health sciences fields.

### **Redefining Solutions—Motivation**

Both ability and motivation must be addressed for lasting, meaningful change to occur. Ideally, the process should be so smooth that injured workers will cease to be frustrated. Here are some basic principles that should be considered:

- \* Injured workers expect that since their employer was responsible for the problem, the employer will be responsible for the solution. A better educational process will help them understand how to realistically maximize the benefits and deal with obstacles.
- \* Every interaction with every person involved in the claim should have a feeling of helpfulness and support.

- \* Replace the term “chronic pain patient” with “injured worker who is experiencing pain that is chronic.”
- \* Provide everyone with assistance in dealing with the stress of being unable to work. Tragically, the workers' comp system creates severe stress and also withholds mental health resources, which could be delivered cost-efficiently in a group setting. Emotional anxiety is so prevalent in our society that it should not be considered a pre-existing condition, and treatment should be included without question.
- \* Pain = Anger = Abuse. If a person is in pain and frustrated they may not be thinking about the needs of their family. By including the family in the treatment plan, we can limit abuse and build support.
- \* Every person must take full responsibility for his or her own anger, particularly when it is magnified by workers' comp. Self-directed resources are readily available.
- \* A little compassion goes a long way. The doctors among us can compare our own stressful experiences to those of injured workers.

What about the motivation of the physicians, chiropractors, and claims examiners? We are often so frustrated by the chaos that we often just go through the motions, not seeing how much there is at stake for the worker in the system. A significant percent of physicians ignore the dreaded paperwork for weeks. Meanwhile a client's stress is skyrocketing.

To improve a worker's motivation, significant advances need to be made and given the highest priority.

### **Summary**

To create meaningful change in the workers' comp system, **both ability and motivation** must be addressed. I believe that health care providers have a responsibility to look at the problems faced by an injured worker, and then frame them through the lenses of ability and motivation. Specific projects can be developed, tested, and implemented. Together, we can find solutions to the problems related to workers' comp and create a brighter future for all on a wide scale.

<sup>1</sup> Patterson, Kerry, et al., “Influencer: The Power to Change Anything.” (VitalSmarts, LLC, a division of McGraw-Hill, New York, 2008)

David A. Hanscom, MD is a board certified orthopedic surgeon specializing in complex spine problems in all areas of the spine. He is the founder of the “DOCC” project, a structured rehabilitation protocol for spine pain. [www.doccproject.com/](http://www.doccproject.com/). He is working with Swedish Hospital in Seattle, WA to improve access to structured non-operative care. He is the founder of the Puget Sound Spine Interest group, a non-profit educational group, which provides a regional forum for physicians to share ideas regarding optimum spine care.

# University Researchers Collaborate to Study Chronic Pain

**A** growing awareness of the massive impact of chronic pain on society is expanding into the scientific community. Medical and scientific researchers are investigating the biology of pain and how it interacts with our brain, emotions, and nervous system.

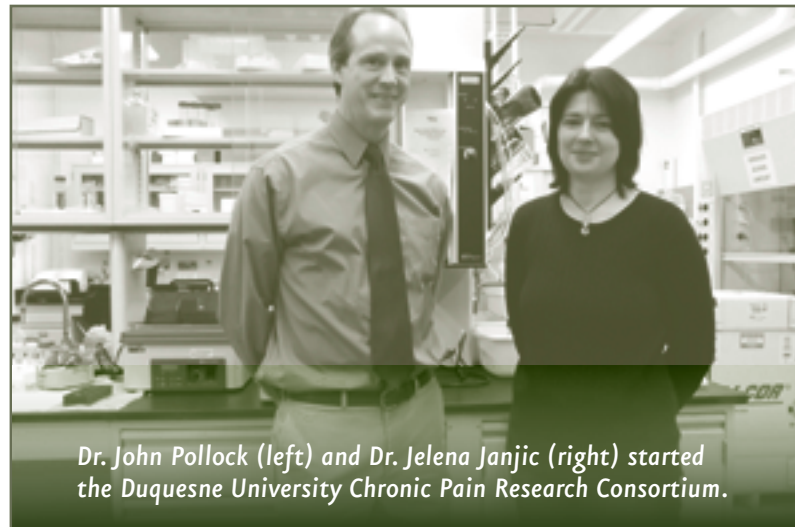
One researcher in Pittsburgh, Pennsylvania is researching how drugs can be made more effective by improving their delivery, aided by modern molecular imaging. Jelena M. Janjic, Ph.D. ([www.duq.edu/pharmacy/faculty-main/janjic.cfm](http://www.duq.edu/pharmacy/faculty-main/janjic.cfm)) is Assistant Professor of Pharmaceutics at the Mellon School of Pharmacy, Duquesne University, Pittsburgh. She researches theranostics, (combining therapy and diagnostic-imaging) to simultaneously deliver drugs to tissues and measure the tissue response. Specifically her interest lies in the interactions between the immune and nervous systems in chronic pain.

Janjic learned 10 years ago that chronic pain was to be part of her personal life. As she researched a broad scientific literature to understand her own pain, hoping to find more effective treatments, chronic pain naturally became part of her professional life. She also realized that her research into immune system responses to cancer could also relate to the cellular and molecular mechanisms of chronic pain. She envisioned that the theranostic nanoparticles she was already working on could be applied to resolve mechanistic questions in chronic pain models.

Then she began to talk to other researchers on campus. In 2011, Dr. Janjic met with faculty members from Duquesne's schools of pharmacy, science, and health science to discuss research interests related to chronic pain.

One of them, John Pollock, Ph.D. ([www.duq.edu/science/faculty/pollock.cfm](http://www.duq.edu/science/faculty/pollock.cfm)) Associate Professor at the Bayer School of Natural and Environmental Science, saw connections between her work and his work in tissue engineering and regeneration therapy. In particular, Pollock is studying the interaction between chronic pain and the peripheral nervous system with a specific focus on how pain-reporting proteins like TRP change their abundance. Changes in what proteins are present in nerve cells seems to be an underlying facet to how chronic pain originates and persists. Such changes may be triggered by inflammation mediated by the immune system. Dr. Janjic pointed out to Pollock that they could 'see' what tissues are experiencing inflammation during pain, which could later be correlated with the changes in protein expression.

The result of this meeting was the Duquesne University Chronic Pain Research Consortium, [www.duq.edu/pain](http://www.duq.edu/pain), now led jointly by Pollock and Janjic.



*Dr. John Pollock (left) and Dr. Jelena Janjic (right) started the Duquesne University Chronic Pain Research Consortium.*

As a group, the members of the consortium, who all reside at one campus, have expertise in pharmacology, medicinal chemistry, molecular imaging, animal behavior, pharmaceutics, immunology, neuroscience, neuropharmacology, and neurobiology. Their research projects range from studying how the immune system, stress and pain systems interact for those with cancer pain, to neuropathic pain, fibromyalgia, and regenerative therapies.

The Consortium has received an Interface Seed Grant, funded by the Pittsburgh Tissue Engineering Initiative, Inc. for \$100,000. Pollock and Janjic will share the grant to study, "Acute to Chronic Pain Transition in Postsurgical Recovery: Combined input from the immune system and peripheral nervous system."

It will explore the molecular biology of nerve cells as they respond to pain (Pollock) and also nanoparticles (Janjic) that have been developed to reveal aspects of the immune system as it responds to pain and inflammation in live animals.

"There are many types of pain that feel different from one another. This is because people's genes and proteins report the different types of pain differently. So we are looking to treat the proteins that communicate the pain, by applying therapy just to the site where the pain originates," said Pollock.

"Sometimes the site of a pain-producing injury continues to hurt after the injury heals, perhaps because of inflammation," Janjic added. "Is it possible that the inflammatory system influences pain far more than we know? And how does that affect the molecules?"

Janjic hopes that this research can lead to therapies that will suppress pain and increase function. "We need to provide people who are managing and living with chronic pain more ways to reduce and eliminate pain," she said.

| TOP |

# ACPA Updates

Welcome to our new groups and facilitators.

**John Owens**  
Tuscaloosa, AL

**Cliff Poff**  
Lafayette, GA

**Donna Erickson**  
Twin Falls, ID

**Karen R. Arnett**  
Coeur D'Alene, ID

**Randolph Rudd**  
Quincy, IL

**Gene East**  
Quincy, IL

**Melissa Anne Majkut**  
Standish, ME

**Cynthia McKenna**  
Rochester, MI

**Daniel L. Radi**  
Crookston, MN

**Lucinda Barker**  
Syracuse, NY

**Liz Walker DeSanto**  
Lancaster, PA

**Diane Broady-Wilson**  
Amarillo, TX

## New 2012 ACPA Resource Guide to Chronic Pain Medication and Treatment

The ACPA believes that people with chronic pain benefit from being well informed about their medications and treatments. This knowledge may relieve the fear and stress that can prevent you from getting the maximum benefits from your treatment. The 2012 ACPA Resource Guide to Chronic Pain Medications & Treatments is available in both PDF and video formats through the [ACPA website](#).

The guide is written, reviewed, and updated yearly by Senior Author Steven Feinberg, M.D., with co-authors Michael Leong, M.D., Andrew Bertagnolli, Ph.D., Kathryn Keller, Pharm.D., Chris Pasero, M.S., R.N.-B.C., F.A.A.N., April Fong, Pharm.D., and Rachel Feinberg, DPT, PT. It also is peer reviewed by the members of the ACPA Professional Advisory Board.

The resource guide describes many treatment approaches to chronic pain. These approaches include passive and active therapies, medications, behavioral-psychological treatments, and a host of other modalities, devices, and interventional techniques including surgery, and other procedures.

The authors believe that rehabilitation through cognitive, behavioral, and physical reactivation treatments (also called functional restoration) often lessens the need for medications and other more invasive procedures. Medications, passive treatments, and invasive interventions alone are usually not satisfactory without the additional use of other active rehabilitation and educational approaches that treat the whole person with chronic pain.

The best approach is for people with pain to ask questions about the benefits and risks or side effects when they are about to embark on any particular treatment approach or new medication. Does the risk justify the possible benefit?

The ACPA Resource Guide to Chronic Pain Medications & Treatments is a supplement and is not meant to serve as medical advice for your condition or medication needs. Remember that the best source of information about your health and medication needs is an open dialogue with your treating doctor.

## Coping Calendar for 2012

For close to 10 years, ACPA members have been looking forward to each year's new Coping Calendar.

The monthly wall calendar highlights a basic coping skill or suggested activity for most days, with a theme for each month, such as assertiveness skills, basic rights, support groups, and positive affirmations. Ideas like "Make a list of what you want to change in your life. Revisit the list frequently," can help people with pain build a more fulfilling life.

You can download and print the calendar from a link on the ACPA website's home page, or at [www.theacpa.org/uploads/calendar%202012.pdf](http://www.theacpa.org/uploads/calendar%202012.pdf).





# ACPA Surveys Reveal Differing Perceptions about Fibromyalgia

New surveys from the American Chronic Pain Association (ACPA) and Forest Laboratories Inc. have found that the way the public perceives fibromyalgia is very different from the way those with fibromyalgia see themselves.

“Many people in the general population have misperceptions about the impact fibromyalgia can have on people’s lives,” says Penney Cowan, founder and executive director of ACPA and someone who has lived with fibromyalgia. “This lack of understanding may lead people with fibromyalgia to delay seeking help and receiving an accurate diagnosis. However, the good news is that people with fibromyalgia, along with their healthcare provider, can learn to manage their condition.”

The survey showed that

*41 percent of the general public believes people with fibromyalgia are courageous,*

while only 17 percent of people who have the condition think of themselves this way.

“Imagine, for some people living with fibromyalgia, having to deal with a persistent pain condition while feeling isolated from society,” says Cowan. “These survey results show that some people with fibromyalgia have misperceptions about how society views them, and our hope is that they learn about these findings and feel empowered to speak openly about their experiences with this condition.”

## **Twelve Million Americans Affected**

Fibromyalgia is a condition marked by chronic, widespread pain and tenderness, decreased physical function, fatigue, and difficulty sleeping. It affects up to 12 million Americans, with an estimated 70 percent of them undiagnosed. It mostly affects women, but can impact men as well.

The surveys, “Two Takes on Fibro: Public Perceptions and Private Realities,” questioned 1,215 men and women diagnosed with fibromyalgia and 1,022 adults from the general population in October 2011.

The two surveys revealed that:

- \* Most of the general population (92 percent) has heard of fibromyalgia, but many do not understand that those with fibromyalgia have difficulty driving, sitting for long periods, and doing household chores.
- \* Many people with fibromyalgia symptoms (67 percent) say they are not satisfied with their ability to carry out their normal routines.

- \* An early fibromyalgia diagnosis is critical, but 77 percent of people with symptoms waited up to three years before seeking help from a healthcare professional.
- \* Seventy percent of people with fibromyalgia hesitated to visit a healthcare professional because they thought their symptoms would go away. Yet once they did seek help, 55 percent said talking with their healthcare provider was a good decision.

## **Fibromyalgia’s Deep, Far-Reaching Functional Impact**

Seventy-one percent of people experiencing fibromyalgia symptoms had difficulty vacuuming, doing yard work, or cleaning their apartment or house. More than half (58 percent) reported they had difficulty lifting and carrying a bag full of groceries or taking out the trash.

Fibro also causes romantic intimacy to suffer, especially among men. Sixty-four percent of people with fibromyalgia who were in a relationship said they experienced difficulty being intimate with their partner.

- \* Among all people with fibromyalgia surveyed, more men (56 percent) than women (48 percent) said it has become more difficult to be physically intimate with their partner.
- \* One in four men (25 percent) and 15 percent of women with fibromyalgia reported that when they were experiencing symptoms, they could no longer sleep in the same bed as their partner.

Fibromyalgia may contribute to decreased income, missed work, increased sick time, and missed career opportunities:

- \* Seventy percent of people with fibromyalgia responded they had difficulty completing tasks at work and 61 percent admitted their work life/career became more difficult because of their fibromyalgia symptoms.
- \* Sixty percent of people with fibromyalgia responded they had to take more sick/personal days and more than half (56 percent) reported their personal income had decreased because of their fibromyalgia symptoms.

Dr. Beth Hodges, a physician with Hodges Family Practice in Asheboro, North Carolina said, “I urge people who think they may have fibromyalgia to seek help from their healthcare provider without delay and maintain an open dialogue. There are FDA-approved treatment options specifically for the management of fibromyalgia. The sooner people with fibromyalgia are diagnosed, the sooner they can begin an effective management plan.”

Read more about “Two Takes on Fibro: Public Perceptions and Private Realities,” at [www.theacpa.org](http://www.theacpa.org) and [www.FibroTogether.com](http://www.FibroTogether.com).

| TOP |





# How to Start a VIP Group in Your Area

by Jani Larsen, National Veterans Coordinator for ACPA and VIP

If you would like to assist other veterans who are beginning their battle of dealing with their pain, start a local Veterans In Pain (VIP) group in your area.

The first step is get in touch with the social worker at your local VA facility. Social workers are a great networking source and can provide you with resources you may not be aware of. They also work closely with local mental health providers and could introduce you to psychologists who might refer clients to your VIP group. They can help you connect with administrators of the hospital's pain clinic, which is also a great referral source.

When you are ready for your first meeting with the social worker, psychologist, or other administrators, bring brochures for both the ACPA and the VIP program. You can order copies of the VIP brochure from [www.vetsinpain.org](http://www.vetsinpain.org) in the "community" section. You can also order copies at [acpa@pacbell.net](mailto:acpa@pacbell.net).

Be sure to give yourself extra time to organize your approach for the meeting. Arrive promptly, (if not early) and have your discussion points clearly in mind.

Take the *ACPA Facilitator Handbook* and at least one *Patient to Person: First Steps* manual. Allow the decision makers to see the extensive resources we can provide and give them a full history of the ACPA. They may not reproduce the manuals in any way; make sure you collect all copies before you leave.



Be sure to review the ACPA and VIP websites before your meetings, as you are the expert and should be knowledgeable on everything ACPA/VIP.

If you have an electronic tablet, bring it along and demonstrate the interactive aspects of our resources for people with pain.

Make sure you mention the great relationship the ACPA has with the Veterans Administration and the VIP groups who have been highly successful in working within the VA.

As the group facilitator, you are also the ACPA/VIP representative and our link to many veterans who need access to our program. Your actions will determine the relationship we have with the VA, and will form their impression of the ACPA /VIP programs.

If you need any information or assistance, please contact me, Jani Larsen. I am here to coordinate communication and resources throughout the Veterans In Pain Program. We have a core group of members that shares the responsibility of planning and hosting the agenda for the meetings that are held on the first and third Tuesday of the month at 3 pm Eastern time on Skype. Please forward your Skype ID to Jani Larsen at [vip@acpa.org](mailto:vip@acpa.org) if you wish to be added to the meeting list.

| TOP |

## Caring for Our Family Caregivers

CONTINUED FROM PAGE 4...

"I think hearing how pain affects so many members' lives gives the caregiver a deeper understanding of what their partner with pain is experiencing," she says. She also encourages caregivers to call the group facilitators if they have questions or problems. Her group has held some evening events that focus on family and other caregivers, including guest speakers from a caregiver support group.

Caregivers benefit from peer support like anyone else—whether it's an occasional meeting at an ACPA group or a separate caregiver-focused group. "It's good to know where to get support, and what problems other people have had," says Dallas. "Just saying something aloud and having someone else say, 'when I had that I did this...' is so valuable."

The caregivers from Steinberg's group also take an important role in outreach activities, including an informational booth at the widely attended Arlington town fair. "We have both

caregivers and people with pain working the booth," Steinberg explains. They can relate to people who are looking for help for a friend or family member at home. "It's helpful for them to be able to talk to other caregivers about their experiences," Steinberg says. "They can learn some basic tips about how to talk to people with pain in a positive way and how important it is to help their friend or relative find a pain support group."

A caregiver can be a trusted partner who's willing to live with you and your pain. These partners on your journey help you devise ways to get things done, remind you to slow down without making you anxious, and support you in ways that go far beyond driving you to a doctor's appointment.

But each partner needs personal time and interests as well as designated time to enjoy life together. Although there will be learning curves and rough patches, you can get through them and find a good life as a couple coping with pain.

| 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:

### AMBASSADOR

Endo Pharmaceuticals  
 Janssen Pharmaceuticals, Inc.  
 Lilly  
 Millennium Laboratories

### EDUCATOR

Cephalon  
 Forest Laboratories Inc.  
 Medtronic Inc.  
 Purdue

### BUILDER

Abbott  
 Archimedes Pharma

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

**Endo Pharmaceuticals:**  
 For the Veterans In Pain (VIP) program.

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

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

**Purdue:**  
 For printing 1,000 of the ACPA workbooks:  
 From Patient to Person: First Steps.

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  
 DR. STEVEN FEINBERG

Given by Brian Grant

IN MEMORY OF  
 RUBEN TENICELA, MD

Given by Darlene Lovasik, RN

IN MEMORY OF  
 ROBERT MOGLEY

Given by  
 Mr. & Mrs. Jack Schoonover

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

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

Please send inquiries to:

The ACPA  
 P.O. Box 850  
 Rocklin, CA 95677

**EXECUTIVE DIRECTOR:**  
 Penney Cowan

**PRESIDENT,  
 BOARD OF DIRECTORS:**  
 Tomio Inomata

**PAST PRESIDENT,  
 EDITORIAL DIRECTOR:**  
 Nicole Kelly

**MEDICAL EDITOR:**  
 Steven Feinberg, M.D.

**COPY EDITOR:**  
 Alison Conte

**SPECIAL FEATURES:**  
 Erin Kelly