



CHRONICLE



The Controlling Factor of Pain

by Penney Cowan, Executive Director, ACPA

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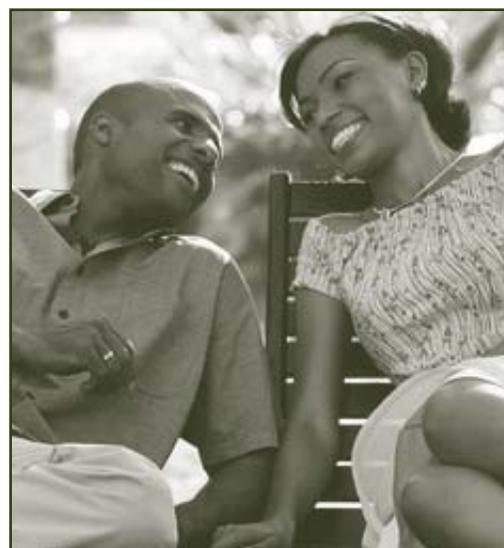
Recently the American Chronic Pain Association developed the Pain Log to help people understand all the factors that have an impact on the level of pain they experience. Things such as activity, exercise, sleep, mood, appetite, stress, financial worries, interaction with others, and alcohol consumption are measured. This long list helps people with pain realize that there are many different aspects of their lives that affect how much pain they experience. One other item we should have put on the scale is *fear*. That should have been on the top of the list.

You might wonder why. We all know that pain is experienced at different levels at different times of the day. We even have days where our pain is manageable. But still, there is always that fear hiding in the background. We have experienced far too much pain to believe that our good days will last. We know the pain will return; it is just a matter of when.

It seems that the fear of the pain is often worse than the pain itself. Fear, for many of us, is the controlling factor. Think about it for a moment. When we are afraid we tend to be on edge, tense, and feel stressed out. Our muscles get tight and we focus on the pain, which increases our sense of suffering.

We know that stress increases pain. We also know that we have the ability to manage our stress, so why not apply those same skills to fear? Can we learn

to reduce our fears—live in the moment no matter what might be ahead—and face each moment with a sense that we are indeed the ones in control? Remember, pain is inevitable but suffering is optional.



My most significant factor in learning to manage my pain through the pain management program—28 years ago—was realizing that I didn't have to fear my pain. I was the one in control. I just had to apply all the skills I learned to ensure that I maintained control. That is one of the main reasons I began the ACPA, to ensure that I would be able to maintain my wellness and keep my fear in check.

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People with Pain Confront Their Fears

by Sally Price

Mention fear to a person with chronic pain and you'll get a torrent of emotions.

For those who have no hope, it's a, "huge, huge fear," said Kathie Hood, facilitator of an ACPA chapter in Danville, California. "Everyone else has a problem but they get over it and get on with their lives. [People with chronic pain] fear it will never go away. They fear it will get worse. They think, 'I can deal with it today, but if it gets worse, will I be able to?'"

"They fear they will lose the relationships that are so important to them. They fear they won't be able to be the grandmother or parent they want to be," she said. Kathie has a 3-and-a-half-year-old granddaughter, and said she steels herself for her visits by taking extra pain medication, explaining, "I so want to be there for her."

There are also social fears, according to Kathie. It is hard to lose old friends who cannot deal with the pain and hard to make new ones. With new or old friends, there's fear that you won't be able to keep dates and enjoy parties. "We fear that we'll not be able to continue favorite activities," she said, citing the needlework and calligraphy she's given up because of chronic neck problems and difficulty holding up her arms.

Fear of Medications

Trish Walch, an ACPA facilitator in Irwin, Pennsylvania, fears that doctors will label her as a drug seeker. After 12 years of taking opioids, Trish notes her doctors' nervousness about prescribing pain medications and their need to protect themselves whenever she has to sign a contract—which occurs every three months. She said, "It makes you



feel you've been singled out and looked down on. You fear at some point they're going to say 'you can't have this anymore.'"

On the other side, some are afraid of opioid medications. Kathie said she had "a fear of taking drugs—a fear of dependency." Now, she said, she makes appropriate use of medications and has overcome that concern, using a positive attitude to find ways to do what she wants to do.

Fearing What Others Think

Worrying about the opinions of others can be very restrictive for a person with chronic pain, who may give up social activities to avoid public reaction. Trish, who has fibromyalgia and is very affected by cold, loves to go to hockey games to watch her nephew play. But she must use cushions, blankets and mittens to sit in "that freezing cold environment" for over an hour. "People don't understand that you're just trying to get through life the best you can," she said. "Most of the time I can rise above it and push on. Other

days I don't feel strong enough to push through that storm."

Trish deals with fear of pain by preparing for bad pain days. She has a reclining wheelchair, walker, and scooter on hand. "Some days I don't need any and other days I need one or the other," she said.

While there's a healthy fear that keeps us from doing stupid things, other fears can be blown out of proportion and control our lives. Memories of when the pain was a 10 (on a pain scale of 0 to 10) can force us into thinking the pain will spike to that level if we exercise, hike, or stretch, making us avoid on these helpful methods of managing pain.

Fear Brings Out Strengths and Creativity

Pat Merritt, an ACPA facilitator in New Jersey, said fear used to rule her life. Twelve years ago, when she first began to deal with chronic pain in her left leg caused by a pinched nerve, she had many disappointments with activities. She said, "It caused me to rethink how I communicate my needs with others. I was challenged to rise to the occasion and ask for what I needed."

Pat used to be afraid to travel "because I knew I would be in pain from sitting, standing, or walking." Now she gets all the information she can beforehand, so she can try to modify things to accommodate her needs, she said.

Sometimes fears can be very concrete, as for Romona Johnson, 44, of Tampa, Florida. Romona suffers from Reflex Sympathetic Dystrophy (RSD), a neurological disorder characterized by severe burning pain, fever, chills, and numbness. Romona said she fears having her leg amputated as the RSD progresses.

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Physical and relaxation exercises help some deal with fear.

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She deals with her pain by painting and lately has been experiencing pain in her right arm. She fears she may not be able to continue the painting that has become so important to her.

For now, Romona paints acrylic abstracts, using colors that express the pain she is feeling. Surrounded by 25 pictures she has painted, Romona recently said, "Painting relaxes my soul. When I'm going through a tough time, I will express what I feel on canvas. It helps me not focus on the pain."

Using Support and Relaxation

Seeking psychological support is an important part of dealing with fear

of pain, whether one sees a counselor or has a circle of friends to talk to and be with. Trish calls her psychologist a valuable part of her treatment plan. "All of us need to have that unconnected sounding board with whom we can express ourselves. The psychologist," she said, "helps me with some of the fears and plans for the future, so I don't fear as much."

Trish said she has found many new friends through her ACPA support group and pain management workshops. "You meet people who understand what it's like and don't judge you," she said. These friends help her deal with her fear of the future, when

her parents won't be around to provide support in her daily life. Physical and relaxation exercises help some deal with fear. Trish uses yoga, Tai Chi, Traiger, and trigger point massage, as well as biofeedback and hypnosis.

Pat said she does yoga and meditation. "I find they help me to calm my body, explore my thought processes and come up with creative solutions to deal with chronic pain," said Pat. A registered nurse, Pat has just opened her own holistic practice so she can balance her pain and patients better. "I now make my own schedule and see clients at a work level I can tolerate." She is certified in aromatherapy massage, reflexology, and guided imagery.

Learning to readjust to the major differences chronic pain makes in a life is important to Kathie, 64, who lives with her husband in Walnut Creek, California. "We have to learn a new balance in our lives," she said.

Kathie's pain began with an accident when she was 18 years old and slipped on a rock, landing on the back of her neck. Now with a fused neck in addition to stenosis of the back and osteoarthritis, she had gained much perspective from observing others in her ACPA group, especially those she feels have much worse problems.

Her years of experiences have led her to her faith, which she sees as a sure cure to fear. "Most of my fear I've been able to handle through my beliefs... God will always take care of me, be with me and have a plan for my life. That really sums it up," she said.



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Research Reveals How Fear Can Create Pain

by Stanley Chapman, Ph.D.

Chronic pain often disrupts almost every aspect of life, so it is natural to experience fear or anxiety (I will use these words interchangeably) in relation to it. We would expect people with pain to worry and to wonder, “How will this constant presence of pain and its limitations affect my future? Will I ever have a good life again?”

This fear is a natural result of pain, but it also becomes a *cause of more pain* and reduced quality of life, in a kind of vicious cycle. Dental hygienists report that people undergoing painful dental procedures report more pain if they are anxious about the procedure. Fearful individuals often develop tight muscles and attend more closely to sensations of pain, both of which can make the sensation of pain worse. When your muscles are tense for a long period of time, your pain levels increase.

Several studies show that anxiety in the presence of chronic pain is a strong predictor of more intense physical complaints and a poorer adjustment (McCracken, et al. 1998, 1999). A 2006 study by Ochsner et al. in the journal *Pain* used a technique called functional magnetic resonance imaging (which traces brain activity) to study responses to a painful heat stimulus applied to the forearm. It found that certain areas of the brain important to pain were activated most strongly in people who were most anxious.

Anxiety Reduces Activity

The anxiety that accompanies pain can increase vulnerability to disease, interfere with needed sleep, increase irritability, and limit social and physical activities. Commonly, people with chronic pain reduce or even cease physical activity out of fear that their condition could be made worse with the wrong movement, even in cases where no such additional harm can be expected. This inactivity then contributes to further disability and depression.

In recent years, there have been many studies of “catastrophizers,” people who represent the ultimate in fear, negative focus, and pessimism. People with pain who catastrophize ruminate on the presence of pain, magnify its negative aspects, and perceive themselves as unable to control pain or related problems. This response pattern is associated with continued severe pain and disability and a much poorer response to medical treatments designed to relieve pain and/or improve function. The research suggests something like a self-fulfilling prophecy: individuals who expect the worst and focus on the negative experience the worst and

have outcomes that are the most negative. [Editor’s note—Many people may respond to life’s challenges this way, not just people with chronic pain.]

Fighting the Fear

How can you combat fear, particularly if it is a natural part of the pain experience? Important steps include:

- * Recognizing fear as a problem to work on
- * Learning more facts about the chronic pain problem
- * Focusing on positive things that you and your treatment team can do to alleviate pain and improve function

It is critical that your health care professionals have the expertise and technical skills needed to treat pain. They should evaluate all components of your condition and thoroughly discuss treatment options with you. You will have better results if you are an active participant in treatment planning and not just a passive recipient of care.

You can also quiet your fears by sharing reactions and experiences with others who have similar problems and have learned positive coping techniques. You can find a support group for a specific painful condition or for coping with chronic pain in general. You can locate ACPA groups at <http://www.theacpa.org/about/groups.asp>.

Learning more about your condition can also subdue anxiety. (Being a member of the American Chronic Pain Association is one excellent step to obtain information and reduce fear!) Some helpful books are: *Managing Pain Before it Manages You* by Margaret Caudill, or *Learning to Master Your Chronic Pain* by Robert Jamison. CONTINUED ON PAGE 5...

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Quiet your fears by sharing reactions with others.

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If you read *The Pursuit of Happiness* by David Myers, you will find that fundamental happiness is dependent on many factors that are not completely prevented by pain, such as close relationships, high self-esteem, meaningful spiritual values, an outgoing nature, taking control of your own destiny, being optimistic, and focusing on the positive aspects of life.

Treatments to Reduce Anxiety

There also are many treatments that can alleviate pain and pain-related anxiety. Research conducted by this author and colleagues in several interdisciplinary pain centers suggests that relaxation methods can help people with pain. These include:

- * Deep breathing and meditation
- * Autogenic training—focusing on feelings of warmth and heaviness throughout the body
- * Progressive muscle relaxation—focusing on sensations while sequentially tensing and relaxing many muscles
- * Imagery—focusing on a scene or image that is very relaxing to you, such as being at the beach or mountains

To be effective with such methods, you have to practice them on a daily basis. When you develop the ability to relax well with use of a brief procedure, you can maintain relaxation throughout the day. You can buy tapes or CDs to guide relaxation, (<http://acpa.stores.yahoo.net/painrelbreat.html>) or learn from an experienced leader.

Biofeedback therapy can help to identify and change physiological aspects of anxiety, such as muscle tension, blood flow, perspiration, and/or brain wave patterns. A machine reads your responses while you work to modify these responses as you view them on a screen.

Relaxation and biofeedback are both examples of cognitive-behavioral therapy, which addresses thought patterns, beliefs, and attitudes (cognitions) as well as behaviors. Such therapy directs you to develop helpful thoughts and behaviors for coping with pain, and dispels the fear that quality of life is impossible with a pain problem. Many factors that affect fear and pain might be addressed, such as proper pacing of activities, beliefs about pain and one's ability to control it, assertiveness, communication skills, and maintaining self-esteem, perspective, and a positive attitude amid loss and change.

In the end, we must understand that fear can be managed and reduced and that doing so successfully is an important part of successful pain management.

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Controlling Factor

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Once we have resolved to understand the role that fear plays in pain, and keep the fear in check, we might actually be able to reduce our sense of suffering.

In this issue of *The Chronicle*, three medical professionals who serve on the ACPA Advisory Committee discuss the effect that fear and anxiety can have on our pain, physically and emotionally. In other articles ACPA members talk about how they have learned to confront and conquer their fears. All point out that knowledge, support groups, and relaxation and pacing techniques are key factors in controlling fear and managing our pain. These are the areas where ACPA can play an important role in their lives and yours.

Additional viewpoints on pain and fear are available in a recent issue of Pain: Clinical Update, a publication of the International Association for the Study of Pain. You can find it at their website, <http://www.iasp-pain.org> by clicking on the Publications link.

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Fear Can Affect Self-Management of Pain

by Gail C. Davis, EdD, RN

Is it possible that the fear of pain can affect how we manage it? The answer is undoubtedly “yes”. The mind can be a powerful force in how we deal with most things in our lives, and how we manage pain is no different.

What “fear of pain” means may be quite different to each of us and it is important to identify this individual meaning to effectively deal with it. We might express our fears with statements like these:

- * Certain movements will make my pain worse or cause reinjury.
- * Pain keeps me from doing what I need to do.
- * I’m embarrassed to use aides or supports (such as a cane or walker) that would allow me to do more.
- * I’m afraid to participate in social activities because this often makes my pain worse.
- * Taking certain medicines will lead to dependence or addiction.

In addition to thinking about and examining our individual pain-related fears, it’s also important to review the meaning of pain self-management. I interpret it as three components: pain relief, pain modulation, and self-efficacy.¹

- * **Pain relief**, easing or alleviating the pain, is most commonly addressed by the use of medicine.
- * **Pain modulation** refers to using a variety of techniques to soften the effects of pain over time and under a variety of circumstances; included are such methods as massage, guided imagery, distraction, and exercise. Each person develops his or her own “bag” of methods to pull from as needed. What we put into this bag



and how successfully we pull from it becomes a very important part of pain management.

- * Essential to this success is **self-efficacy**, or the belief that a technique can be performed.

This is where fear plays a huge role and why recognizing and dealing with fear becomes so important. If you fear that you “can’t do it,” you’re more likely to avoid trying to do it. For example, if you believe that exercising or participating in social events is going to make your pain worse, you’ll avoid these activities. This avoidance will likely lead to your becoming more physically disabled, more isolated, and more depressed. The overall intensity of the pain may also increase if you avoid taking medicine or wait to take it until pain is at its worst.

Anxiety in Social Situations

Socially related fears are common with pain; these fears often overlap

with fears of embarrassment or of not pleasing others. This might be expressed as, “I didn’t go shopping with my friends because I was afraid that my pain would get worse” or “I was hurting so bad when I got home from shopping, but I didn’t want my friends to know how I felt. I know I’ll pay for this for a few days.”

This fear may lead to social isolation in the first example or to exacerbation of pain in the second. The fear of not pleasing others—rather than assertively stating what your realistic limitations are and planning activities accordingly—can have an extremely negative impact on pain management. The fear of embarrassment—because you need to use adaptive resources—is a socially related fear that can also lead to social isolation and prevent you from going places, staying connected with friends, and enjoying activities you love.²

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New Situations Can Cause—or Conquer—Fears

by Maggie Chesnut

I remember the terror of turning off the highway. The feeling in the pit of my stomach swelled as we neared the turn, a mixture of excitement and nausea. I tried not to think about it as final, but as a temporary residence. Still, I didn't feel like I was arriving; it felt like leaving.

I've never felt more alone in my life than when I watched the family van turn the corner, leaving me at my new college. Even in middle school when I was too scared to tell anyone about my pain, I still had my parents. Now, I was on my own.

Despite my fears, I jumped up from my new bed when my new roommate walked in. I was excited to meet her because she had celiac disease as well, she was from the same area of New York, and our names were very similar. Naturally I thought we'd be best friends.

We had corresponded through email over the summer and, predictably, the main topic was celiac disease. I had never met another person with celiac disease, even after starting ACPA's [Growing Pains](#), a support group for chronically ill youth.

While I was misdiagnosed for seven years, my roommate was diagnosed at age two, with the typical bloated belly and short limbs that result from malnourishment. However, her entire family had chosen to adhere to a gluten-free diet. We discussed our experiences, our fear of becoming ill, and our various restaurant stories. We described our diets, compared



Maggie Chesnut, coordinator of ACPA's Growing Pains, is feeling at home in her college dorm room.

our favorite gluten-free products, and even mused about the possibility of starting a support group at school.

Everything seemed wonderful. But my interactions with my roommate sparked a monumental realization. As our conversations continued, I realized we were completely different people. The only topic we could agree on was how delicious the gluten-free brownies were. It struck me that I am a complete person, not just a disease.

explored my options. But now, I came to realize that while much of my college search was based on the celiac diet, my friendships do not have to be.

There are so many other unique aspects of my person besides my disease. I want people to spend time with me because of who I am, not how I am diagnosed. My roommate and I are no longer roommates. I am growing fast, surpassing previous understandings of my pain and myself.

“There are so many aspects of my person besides my disease.”

Just as a person without celiac disease would not go to a college that could not feed them, I would not go to a school that does not provide me with my basic nutritional needs. The competition for the most selective name-brand schools is consuming, and it is often easy to forget that you are in control. When I was searching for colleges, I voiced my needs and

I am able to grow because I found a place that fits me, where I can move beyond my disease. I do not pretend to have reached a plateau of enlightenment, but I know from now on I will negotiate every new situation with the confident voice of a person with celiac disease, not a celiac.

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Diagnosis and Treatment of Anxiety Disorders in Chronic Spinal Pain

by Carlos F. Tirado and Rollin M. Gallagher

People with chronic painful spine conditions are anxious, and for good reason. Uncertain about the cause and eventual outcome of their spine disease or spinal injury, they may worry about its affect on their and their families' well being.

- * Will they be able to work and cope financially?
- * Will the stress of pain and disability interfere with recreational activities and important relationships?
- * Can they remain sexually active and emotionally intimate?
- * Will they become more depressed?
- * Which of the many treatment options should they pursue and will they have access to the best treatment for their conditions?

This situational anxiety often worsens pain or contributes to morbidity and poor treatment outcomes. Uncertainty in the healthcare system also contributes to anxiety, both directly and indirectly. Despite advances in diagnostic and therapeutic spine medicine, which create hope and relief for many with spine pain, healthcare systems are notoriously unable to adequately manage chronic spine pain.

High rates of spinal injury continue, and are often slow to be identified and correctly treated. In addition, successful chronic pain management, which requires attention to all the biopsychosocial factors affecting pain and its consequences, is beyond the scope of most physicians, most spine treatment centers, and many healthcare organizations.

When pain and its emotional effects are not controlled, a new neuropathological process, independent of the initial cause, may lead to the development of pain as a disease of the central

nervous system with changes in the actual anatomy and physiology of the brain and spinal cord. These changes cause the pain signal to be permanently turned on, similar to a light or another electrical appliance with a faulty switch that is stuck on. Anxiety, through its activation of the sympathetic nervous system, acts to turn up the pain signal, much like a rheostat in an electric light. These cases may require sophisticated and intensive management by a comprehensive pain medicine center, generally not available to the public.

Dysfunction in Healthcare Leads to Anxiety

We are seeing increased dysfunction in the present healthcare delivery system, which perpetuates the uncertainty in the management of spine pain. Healthcare institutions are governed by business principals of revenue generation and expense reduction instead of long-term evidence of functional recovery and patient success rates. To maintain economic viability, pain treatment centers must emphasize well-reimbursed procedures. They de-emphasize time-consuming chronic disease management approaches that are poorly reimbursed, and thus not available, even for Americans with excellent insurance. This dysfunction leads to more uncertainty and anxieties, as patients lose faith in their caregivers. So we have three sources of fear and anxiety.

- * Persons with spinal pain are uncertain and fearful about their own and their family's future.
- * The physician treating pain is uncertain as to how to proceed with treatment once initial treatment has failed.
- * Even policy-makers, governmental agencies, and insurers, beset with



competing interests and the need for economic viability, are uncertain about the most effective strategies and policies.

But, there are ways to manage the problem of fear and anxiety in people with spinal pain, even within this insecure and anxiety-provoking healthcare environment.

Effectively Treating Fear of Pain

Acute anxiety in reaction to pain, stress, and fear may be effectively treated by providing information about the condition and its treatment and by reassuring the patient that he or she will not be abandoned to agonizing pain.

Anxiety is contagious, and insecure physicians can transmit uncertainty to their patients. In turn, insecure patients and their resulting behavioral strategies—which they cannot control, such as becoming demanding or refusing to participate in necessary aspects of care—can exasperate physicians. A kindly, explanatory bedside manner calms the patient and, when necessary, benzodiazepines are situationally very effective, with the caveat that their use for more than four weeks carries an added risk of addiction.

If anxiety persists or if screening questions suggest a specific chronic anxiety disorder, patients should be

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treated by a clinician who can manage the psychopharmacology of each disorder.

Knowledge Combats Anxiety

Patients with specific anxiety disorders respond well to anti-anxiety medication regimens that are specific for that particular disorder, as well as to the short-term use of benzodiazepines. Selectively and skillfully integrating anxiolytic treatment with psychotherapeutic treatments, such as coping skills training, including cognitive behavioral therapy and relaxation, usually confers the greatest benefit. Creating attitudes of self-help through knowledge and behavioral pain management training will complement the selective use of anxiolytics. For a [list of websites](#) that provide information about pain and can be used to further self-knowledge,

go to www.theacpa.org, and click on People with Pain/Resources.)

A prevailing challenge to spine medicine is the mobilization of the needed resources to coordinate effective treatment for anxiety with the treatment of spinal pain. The advent of evidence-based medicine, with reimbursement increasingly determined by outcomes, rather than procedural credentialing, encourages physicians to address more effectively the anxiety associated with spinal pain.

Rollin M. Gallagher, MD, MPH, is Director of The Center for Pain Medicine (part of the University of Pennsylvania Health System), Clinical Professor of Psychiatry at Penn and Director of Pain Medicine at the Philadelphia VA Medical Center.

Excerpted from Chapter 15, *Interventional Spine: An Algorithmic Approach* Editors: Curtis Slipman, Rick Derby, Frederick Simeone, and Tom Mayer. New York: Elsevier (expected publication date, July 30, 2007)

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Self Management

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Fear of pain, then, can become a major barrier to how chronic pain is self-managed on a day-to-day basis. Fear sends internal messages that interfere with taking positive steps. Turning negative or fear-related messages into positive ones is an important phase of your progress. When fear is linked to certain activities, the link can only be broken by taking graduated steps that are guided by self-defined goals. When these goals are individually set, they are more likely to motivate you to achieve them. Motivation combined with self-efficacy increases goal attainment.³

Set Goals and Believe in Achievement

The underlying lesson related to fear of pain and its self-management is that fears can be acknowledged and positively addressed. To achieve this

Fears can be acknowledged and positively addressed.

requires motivation, the belief it can be done, and realistic goal setting. Once realistic short-term goals are achieved, they can be raised to a higher level as appropriate.

For example, a beginning goal might be to walk a half-block three days a week within a two-month period. If you achieve this goal by the end of two months, you can revise it so you walk further and/or walk more often. The same kind of approach can be taken to learn other strategies such as guided imagery to relax, planning activities to better pace yourself, or developing assertiveness in explaining your situation to others.

As goals are met and you feel comfortable using new techniques, add these to your "bag." Try to keep it filled

with self-management strategies that are *right for you* so they can be pulled out and used when needed.

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ACPA Update

New ACPA Groups

Welcome to our new groups and facilitators.

Dale Mallone
Fullerton, CA

Jillian Browne
Justin, CA

Kristi Dalven
Long Beach, CA

Kathy Eggebrecht
Orange, CA

Francine Silverman
Deerfield, IL

Samantha Nagy
Rogers City, MI

Laurel Jerin
Mayfield Heights, OH

Margaret Matthews
Falls Church, VA

Lynn Streu
Leesburg, VA

Bob Zgne
Woodbridge, VA



ACPA Builds Links with Emergency Physicians

The emergency department (ED) may be all too familiar to people with chronic pain, but many emergency department staff members are less familiar with the needs and expectations of people with pain. The ACPA will begin to address this gap this fall by presenting a poster of the results of our ED study and having a booth at the national meeting of the American College of Emergency Physicians (ACEP) Oct. 8-11, 2007 in Seattle, Washington.

The event is part of an ongoing project, underwritten by Cephalon, to help make communication between people with pain and the ED staff more effective. It is expected that 5,000 emergency physicians will attend this year's conference.

Pain Awareness Month Tool Kits Available Online

September is Pain Awareness Month and the ACPA has tool kits that can be used by nurses, pharmacists, and others to draw attention to and build understanding of pain issues on a local level.

Visit our web page at www.theacpa.org, click on Partners for Understanding Pain on the home page, then Information and Advocacy to [download your tool kit](#). You'll also find information there about creating awareness about pain in older adults.

ACPA/Kaiser Partnership

This fall, the ACPA and Kaiser Permanente Health System will pilot a program to provide support to people being treated for pain issues in certain Kaiser facilities. Penney Cowan will conduct training sessions for Kaiser staff members and patients in the pain management skills ACPA teaches in California and the Washington, D.C., area. The goal is to prepare individuals to take an active role in maintaining wellness through ACPA support groups.

The ACPA welcomes inquiries from other health care facilities with an interest in a similar program.

ACPA and AgrAbility

Farming continues to rank as one of the most dangerous occupations in the U.S. Injuries are common and farmers struggle each day to cope with arthritis, knee, and back problems—to name just a few—that are caused by the daily demands of production agriculture. The AgrAbility Project is a national initiative of the Easter Seals Society, underwritten by the United States Department of Agriculture. It provides education, resources, and support to farmers and ranchers with disabilities. The ACPA is proud to join in this effort.

We are currently seeking funding to work with the AgrAbility staff to identify 10 areas in the country where the ACPA can work with local farmers and ranchers. We will train injured farmers and ranchers in the basics of pain management and help them establish support groups in their communities. If this initial project is successful, we hope to expand the project in the years to come.

National Pain Care Policy Act Introduced in the U.S. House of Representatives

In mid July, Representatives Lois Capps (D-CA) and Mike Rogers (R-MI) introduced the National Pain Care Policy Act of 2007, which would improve pain care research, education, training, and access. The pain community has been instrumental in joining forces to support and advance this important legislation. This bill is a reintroduction of HR 1020 and includes many of the earlier bill's key features. The new bill is known as HR 2994.

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The National Pain Care Policy Act of 2007 summary states:

Pain is the most common reason Americans access the health care system and is a leading contributor to health care costs. Pain is also a leading cause of disability. Most painful conditions can be relieved with proper treatment, and providing adequate pain management is a crucial component of improving and maintaining quality of life for patients, survivors, and their loved ones. Yet people in pain often face significant barriers that can prevent proper assessment, diagnosis, treatment and management of their pain. The National Pain Care Policy Act of 2007 is designed to address many of these barriers by improving pain care research, education, training, access, outreach and care.

The bill, if passed, would:

Authorize an Institute of Medicine Conference on Pain Care to:

- * Increase awareness of pain as a significant public health problem;
- * Evaluate the adequacy of pain assessment, treatment and management;
- * Identify barriers to appropriate pain care;
- * Establish an action agenda to address barriers and improve pain care research, education, training and clinical care;
- * Highlight disparities in pain care specific to populations that are disproportionately under-treated for pain; and
- * Report to Congress on findings and recommendations.

Provide a statutory base for the trans-institute Pain Consortium at the National Institutes of Health to:

- * Establish and maintain a coordinated national agenda for basic and clinical research on pain causes and effective treatments;

- * Promote integrated pain research, training and related activities across NIH institutes, centers and programs;
- * Convene an annual conference to assess and make recommendations for NIH pain research and program activities; and
- * Establish a multidisciplinary Consortium Advisory Committee.

Improve health professionals' understanding and ability to assess and appropriately treat pain, and:

- * Require the Agency for Healthcare Research and Quality (AHRQ) to collect and disseminate protocols and evidence-based practices regarding pain; and
- * Authorize the Health Resources and Services Administration (HRSA) to provide grants for development and implementation of programs to educate and train professionals in pain assessment and care.

Require the Secretary of Health and Human Services to develop and implement a national outreach and awareness campaign to educate consumers, patients, families and other caregivers on the:

- * Significance of pain as a national public health problem;
- * Risks to patients if pain is not properly assessed and treated;
- * Availability, benefits, and risks of treatment and management options;
- * Importance of having pain assessed and treated;
- * Role of pain management specialists;
- * Resources available to patients and other consumers to help in dealing with pain; and
- * Prevalence and causes of disparities in pain management among underserved populations.

In designing the program, the bill emphasizes the need to reach underserved populations and to provide

resources that will reduce disparities in access to appropriate pain treatment.

To learn more about the bill, visit the American Pain Foundation web site at www.painfoundation.org.

To voice your support for the bill, contact your own representative.

You can identify him or her using the US House of Representatives web site: www.house.gov and clicking on "Representatives" or "Representatives by State."

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

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

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Sally Price: Look for the Blessing

by Alison J. Conte

Sally Price is a familiar name to readers of the *ACPA Chronicle*. For eight years, she's been interviewing people with pain and sharing their stories. But who is the woman behind the byline?

Sally, 62, of Newport News, Virginia, has led an ACPA support group for 12 years and lives a full life, despite having had chronic pain for 28 years.

She had scoliosis and a back injury followed by back fusion treatments and surgery to implant a pain pump. "It didn't cure the pain, I just ended up with a very stiff back," she recalled. "I was going to have to live with pain."

Needing a different type of job to accommodate her back pain, she went back to school in her late 40s and earned a master's degree in occupational therapy. Working as an OT, she tried pain support groups but her initial experiences were disappointing, "I wanted advice from someone with pain who knew what I was going through."

She discovered this in ACPA and started a support group in Newport News for her patients who were injured on the job. "I showed them that you could work at a job, even with pain," she said. Currently, the monthly meetings have six core members who attend regularly and have helped many others "graduate." Still others stick around to help newcomers.

"If new people join us, we discuss and share their problems and give them the help they need," said Sally. "We use the ACPA manual and work kits as back up, but I don't want to be a teacher. I just want to keep the discussion going."

She brings in speakers, from pain doctors, physical therapists, and psychologists, to disability advocates,

lawyers, and assistive technology specialists. One speaker was a clown, in full costume, who lived in constant pain and used a wheelchair. "She brought out the child in all of us," Sally recalled.

"New people are so glad to find us," she said. "We are the first place they've been to where people understand. They are relieved to be believed and not thought of as crazy."

Acceptance Comes First

Accepting the pain is the hardest and most important lesson. "We can spend a long time looking for the magic cure," she said. "I tell them, 'We are here to help you live with it,' and that isn't always what they want to hear."

"Penney [Cowan] was right to make acceptance the first step," said Sally. "Accepting the pain allows you to go on and live your life. But you have to do it every day."

For Sally, it was not just accepting herself as a person with pain; she also had to learn to live as a grandparent with pain. "I wasn't going to be able to lift the children or be on the playground for a long time," she realized. "You have ideals of what you want to be and all of those roles affect other people. The grandchildren don't always understand."

Her husband, John, also adapted to having a wife with pain, as it affected their social and home life. "He spends a lot of time waiting for me, but he's terrific. He's stuck by me."

Sally continues to follow her dreams and has found ways to do the things she enjoys, using adaptive tools and planning ahead. "We took a cruise to Alaska, which would be wonderful for anyone with a disability. There is no

tight schedule, no unpacking, but you still have the ports, destinations, and on-board activities. When you need to, you have lots of places where you can lie down."

Writing About Other Lives

A former newspaper reporter and freelance writer, Sally began writing for the *Chronicle* after she met ACPA Executive Director Penney Cowan at an ACPA retreat. "I love meeting people from all over the country, finding out about their stories," Sally said. "In interviewing them, I must gain their trust—it helps that I've experienced the same trip."

When she's not writing or running her support group, Sally reads, enjoys family, and going out to eat or to the theatre. "I have a wedge that allows me to watch a show without pain. I carry it with me on a luggage carrier and I lie down on the floor in spots designated for people with wheelchairs."

Her wedge allows Sally to get out and take part in life. While she puts up with some strange looks and remarks, she's learned not to care what people think. She also deals with comments when she walks from her car after parking in a handicapped parking spot. "It's an opportunity to educate people about chronic pain and eventually they accept it."

"One thing I especially enjoy is going to church and Bible studies. The Lord Jesus Christ is an important part of my life. He truly keeps me going," she said.

Sally's personal slogan—Look for the Blessing—is a message to seek out the positive and be open to the good things in life, a lesson she conveys in her work with the ACPA and everywhere else.

Book Reviews

The Savvy Woman Patient: How and Why Sex Differences Affect Your Health

*Edited by Phyllis Greenberger, MSW,
with Jennifer Wider, MD*

Reviewed by Brenda Hendricks

Women and men are different. Unfortunately health care providers have not always recognized how these differences can affect health and should govern care. Researched and written by the Society for Women's Health Research and based on its almost 15 years as a research advocacy organization, this comprehensive guide provides real answers to vital questions that affect a woman's health from young adulthood to menopause and beyond.

F. Haseltine, PhD, MD and founder of the Society for Women's Health Research, states that this book's goals are to "offer a better understanding of diseases that affect men and women differently, to show how much research is being done on all of the conditions that affect women, and to show how all our lives are being improved by that research."

This book is written in down-to-earth language that anyone can understand. It has interesting stories cited by real women like Ruth Ginsburg, associate justice of the U.S. Supreme Court. It discusses diseases, risk factors, symptoms, diagnosis, and treatments, and why your sex matters.

The book tells us about tests we should have to keep us healthy at different ages. It also examines the future of women's health and how important research about women's health can affect our future. This book is an excellent resource for women. In my

opinion the goals were definitely met. According to the Society's web site, *The Savvy Woman Patient* covers sex-based biology, family histories, women's special nutrition, exercise, preventive measures, and aging process, as well as diseases and conditions that affect women differently than men.

The Savvy Woman Patient: How and Why Sex Differences Affect Your Health; published by the Society for Women's Health Research, ISBN: 193310208X. \$13 per copy when ordered from www.womenshealthresearch.org

The Miracle of the Breath: Mastering Fear, Healing Illness, and Experiencing the Divine

By Andy Caponigro

Reviewed by Margaret Reilly-Sabourian

This is an excellent book for people who live with chronic pain and recommended reading for anyone who wants to explore the power of meditation and breath work that is given so freely to all of us. This book is a wonderful opportunity to start learning the

hidden healing qualities that one's own breath has to offer.

Andy Caponigro offers different styles of breath work that are simple for beginners to understand. He then offers more advanced techniques as the reader goes along in his book. You really get the sense that he is traveling right with you, gently teaching and adding to your knowledge. You feel no rush to go to the next step because one of the basic lessons is to use breathing to become content in the moment.

This book could also be used as a reference tool for improving or honing one's breathing exercises on any given day. *The Miracle of the Breath* explores the importance of breath not only to physical well being but as a main conduit of divine energy. Replete with stories and case studies of people healed of asthma, arthritis, anxiety attacks, and other physical and mental traumas through proper breath work, the book also examines the concept of breath as a spiritual life force, according to reviews on Amazon.com.

352 pages; \$15.95 from New World Library
(February 9, 2005) ISBN-10: 1577314786

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Tributes

In Memory of
RON SLOMKOWSKI
 SURVIVED BY DIANE SLOMKOWSKI

Given by
 Craig and Haleen Holt

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The ACPA is a peer support organization: we help each other learn to live fully in spite of chronic pain. We also need to join together to make sure the ACPA continues to be there for us all with resources, materials, and that personal contact that can make such a difference.

Your membership, donations, and purchase of materials keep the ACPA alive and reaching out to even more people with pain. Thanks for helping us help others.