



# CHRONICLE



## Lest we forget . . .

by Penney Cowan, Executive Director, ACPA

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We are dedicating this issue to the men and women who have bravely served our country to ensure that each one of us will continue to enjoy the freedoms we cherish.

very special kind of individual to be so dedicated to a mission that they relegate their own health and well-being to a lower priority. These are true heroes and we need to do all we can to let them know how much we



Most of them entered into the service as able-bodied men and women with young, healthy bodies. Did it occur to them what might happen if they suddenly would be less than able-bodied?

While some might have considered the dangers of accident and injury, I doubt they dwelt on the possibility of returning home to a life lived with some level of constant pain. Yet, many of our veterans endure, and must learn to manage, their chronic pain.

I cannot even begin to imagine the grueling, physical demands put on those who served this country in recent years or in the past. It takes a

appreciate their sacrifice. But we know that our appreciation, expressed through words alone, will not help them live with pain.

At the ACPA national office we receive calls daily from veterans who are looking for help in managing chronic pain.

Commonplace activities that they didn't used to think twice about are much harder now. They are hoping that we might have the answer—whatever that might be—to help them regain the life they had before the pain.

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# ACPA Focuses on the Complex Issue of Veterans in Pain

by Alison J. Conte

In Fall 2010 the American Chronic Pain Association (ACPA) appointed Jani Larsen to coordinate efforts for ACPA support groups in U.S. Department of Veterans Affairs (VA) medical facilities or Vet Centers. As ACPA's regional director for veterans, Jani has a special viewpoint and a lot of useful information to share with veterans.

Jani has had chronic nerve pain since 1998. She served in the military from 1983-1986 in Panama and Honduras during the Contra/Sandinista war and is well acquainted with the problems of veterans with pain. She has been the facilitator of a support group at the VA Hospital in Madison, Wisconsin, since 2004.

"My first priority is to help vets to navigate the VA healthcare system, to provide direction and resources," Jani said. "I'm collecting and sharing best practices for these support groups. I hope this will lead to stronger working relationships between services throughout the VA system."

## Like Anyone Else with Pain

"The biggest problem veterans with pain have is the same problem that the general population has, overcoming the barriers and stumbling blocks to finding treatment," said Dr. Tim McNulty, physical medicine and rehabilitation physician at VA Butler Healthcare in Butler, Pennsylvania.

He explained that veterans are often faced with a complex array of physical, mental, and situational issues that affect their health, how they feel, and how they are treated for pain. "A vet's condition is rarely straightforward," said Dr. McNulty.

While some returned veterans may be dealing with Post-Traumatic Stress Disorder (PTSD), almost all face emotional upheaval when they leave the service. For veterans with chronic pain,

this can compound their condition, make their symptoms hard to identify, and affect their ability to manage pain.

Dr. Roger Brooke, PhD., ABPP, is director of military services for the Duquesne University Psychology Clinic in Pittsburgh, which offers free counseling and support to military service members and their families.

He said that veterans who return to civilian life often feel alienated. "There is frequently a sense of not fitting in, entering a foreign culture. They expect to return to the life they lived before their service, but they are no longer the person they were," he said. "There is a lot of anger, depression, irritability, mood changes, even in the absence of PTSD."

In moving from a civilian to a soldier and then to a veteran, former servicemen and women may be faced with unemployment, marital discord, and/or drug abuse. These feelings can be intertwined with chronic pain and have an impact on the ability to have a productive life.

## Growing Past Adolescence

"Military service will turn a boy into a man," Dr. Brooke said. "They've faced mortality and are more mature as a result."

Jani agrees. "They miss the camaraderie they left behind. Some don't feel as close to their families as they did to those buddies," Jani said. "If their buddies were killed in action, vets may hold back from forming new relationships because they've seen what can happen."

Jani has seen how these stressed emotions can crack further in a crowded, impersonal doctor's office.

"Some veterans tend to blame it on the system. Frustrated with an hour-long wait to see the doctor, one veteran told me he began his office visit in an angry

mood. He said, 'My doctor's not listening to me,' when in fact, he didn't fully communicate his needs. In the end, he didn't get what he came for and wasted a visit," she said.

Another person insisted to her physician that her stimulator was hurting more than helping, Jani said. "She changed her opinion of the physician, just because he was resolute about leaving her stimulator in. She made comments about her faith in him as a doctor, but the conflict was really about just this one issue," she said.

"I had to remind her of her rights as a person with chronic pain and restore her faith in this physician, whom I have seen in the past. I had to remind her how busy they are and that whatever that she could do in advance to prepare herself for the visit would make things go smoother," she said.

## Communicate Constructively

Jani says many veterans are plagued by the feeling that their doctor is not listening or doesn't care about them. "The system is so overburdened, everyone is feeling lost and rejected. We need to do our part by getting back to the basics, working on goals and communication."

"It also helps to log the times when the pain spikes so you can report this to the physician in an objective way."

When veterans are trying to integrate back to civilian life, Dr. Brooke reminds them that this is another journey, one that can be just as demanding and challenging as their military service was. "Don't put your military values behind you," he advises veterans. "Continue to use the characteristics of a soldier or marine: discipline, perseverance, courage, and structure. Integrate these experiences into the rest of your life. Turn the unforgettable trauma into acts of memory."

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### **For Veterans, Pain is Hard to Acknowledge**

All these readjustment factors can affect mental and physical health and exacerbate pain. Some veterans, particularly men, would rather ignore pain than see a doctor. Some feel like their pain is no big deal compared to a soldier they served with who is now missing a leg or died in battle.

“They may not ask for help. There is a taboo on asking for help, admitting pain. In the elite units especially, soldiers don’t complain and minimize the pain they have,” Dr. Brooke said.

“They are also commanded to look after their bodies, to keep this part of their ‘weapon’ healthy. But they also learn to ‘suck it up’ and ignore pain and injury if they have to,” he said.

When veterans do seek help, their training can help them take an active role in their pain treatment. “Soldiers have control over their lives and are responsible for themselves and their buddies. This attitude is one that can translate into being a responsible member of the health care team,” Dr. Brooke said.

### **Support Groups Offer Understanding**

The shared experience of combat results in veterans being a closely knit group, loyal and supportive to each other.

According to Jani, ACPA support groups work because many veterans will listen to and believe other veterans more readily than they will their doctors.

“Vets communicate in their own language, their own shorthand. Even if they fought in different wars, through different branches, they’ve been through similar things,” she added.

The Madison group has had up to eight members, mostly drawn from the patients at the pain clinic. “The chance to interact with other veterans is a key draw. They are missing the camaraderie of service and these other vets understand what they are going through,” she said.

“They are direct about their goals and needs. They want to know why they have the pain and get help to get rid of it. They want their life back, so we go through the steps from patient to person,” Jani said.

Because the support group meetings are held at the VA hospital, Jani can ask physical therapists or occupational therapists to attend and talk about posture or demonstrate assistive devices.

But it is hard for veterans with pain elsewhere in Wisconsin to get to Madison. Some disabled veterans are homebound and paid reimbursement is available for transportation for medical treatment, not for support groups.

The ACPA is investigating video and Internet options to connect with clinics elsewhere in the state.

Vietnam era veterans, now in their 50s and 60s, are more likely to seek personal interaction, according to Jani. This socialization is important for people with pain, but Iran and Afghanistan veterans aren’t joining the VFW. “They socialize through the Internet, like others of their generation. So we will work to reach them there,” Jani said.

### **Getting Connected with VA Services**

Jani Larsen works with her support group members to help them understand the VA system. “It depends on what your service-connected disability is and the level of care you need. The first step is getting your disability reviewed so you can get a diagnosis and begin treatment,” said Jani.

Older veterans who have lived with minor pain for a long time may not easily admit that their pain is worse and impairing their ability to function. “We work to send the message that it is important to talk about your pain and let us help you treat it,” Dr. McNulty said.

### **Team of Specialists Plan Treatment**

At VA Butler, like most VA facilities, the diagnosis begins with an extensive evaluation. “Everyone who comes in is asked if they have pain,” McNulty said, explaining that the VA regards pain as the fifth vital sign, which, along with blood pressure, pulse, respiratory rate, and temperature, can give an indication of health status. “We are prepared to acknowledge, without question, that a person has pain. If pain is a problem to you, we will work with you to help,” said Dr. McNulty.

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## ACPA Focuses on the Complex Issue of Veterans in Pain

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An interdisciplinary team of nurses and doctors could include a psychologist, speech therapist, physiatrist, audiologist, social workers, vocational rehabilitation counselors, and other specialists as needed. The team discusses each person's condition and plans a course of treatment. The veteran with pain will participate in his or her care and follow an integrated course of treatment.

Though each individual charts his or her own course, treatment often involves physical and occupational therapy, medication, bracing, exercise, and injections. Some are referred to a more specialized pain clinic at the VA Pittsburgh Healthcare System.

Veterans can also attend a VA Butler Chronic Pain School, every Thursday afternoon. "These sessions give us more time to explain issues at length, time for real education," said Dr. McNulty.

Chronic Pain School classes might feature a physical therapist talking about home exercise, a behavioral health therapist discussing coping skills and adaptive measures, an occupational therapist on joint protection, energy conversation and adaptive mechanics, and a pharmacist reviewing the proper use of medications.

The VA also offers a back conditioning school over 12 weeks to increase flexibility and core strength, minimize back pain, and prevent reoccurrences. Both "schools" are free to veterans.

"At the VA, veterans need to understand that they aren't the physician's only concern that day. So many people flood the system, it's difficult to respond to each individual. You need to make sure your care doesn't fall through the cracks," Jani said.

**The U.S. Department of Veterans Affairs (VA) provides benefits for men and women, spouses, children, widowers, and widows, including disability benefits, education, training, vocational rehabilitation, employment, insurance, loans, and medical treatment. About 5.5 million veterans receive care each year at more than 1,400 hospitals, outpatient clinics, community living centers, domiciliary care, or readjustment counseling centers. Veterans who have chronic pain can take advantage of these medical and wellness benefits at low or no cost, whether or not their pain is related to combat.**

**Dr. Timothy McNulty is a physical medicine and rehabilitation physician at VA Butler Healthcare. He is a member of VA Butler Healthcare's committee on pain management, working to help identify and and treat veterans with chronic pain.**

**A graduate of the University of Pittsburgh School of Medicine, he did his residency at SUNY Buffalo Affiliated Hospitals.**

**Roger Brooke, Ph.D., ABCP, is a graduate of the Universities of Cape Town and Witwatersrand (Johannesburg), and received his Ph.D. from Rhodes University, Grahamstown. Since 1994 he has been a professor of psychology and director of clinical training at Duquesne University. He is board certified with the American Board of Clinical Psychology, and in 2005 he was elected to the board of directors of the American Academy of Clinical Psychology. His clinical interests include psychotherapy, geropsychology, trauma (especially soldiers' trauma) and psychological assessment, including neuropsychology.**

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### Veterans' Resources

Veterans can locate the pain services within the system and find out more about pain management through VHA Pain Management at [www.va.gov/painmanagement](http://www.va.gov/painmanagement). There you can join a mailing list to receive updates about pain management or review research papers, VHA directives, and safety alerts.

The My HealthVet website at [www.myhealth.va.gov](http://www.myhealth.va.gov) provides wellness information, and a personalized health record that empowers veterans to become informed partners in their health care.

You can also review the VA/DoD Management of Post-Operative Pain Clinical Practice Guideline to assist people and their clinicians in the assessment and management of their pain.

[www.healthquality.va.gov/Post\\_Operative\\_Pain\\_Management\\_POP.asp](http://www.healthquality.va.gov/Post_Operative_Pain_Management_POP.asp)

Other Sites of Possible Interest:

Veterans Health Administration (VHA): [www1.va.gov/health/index.asp](http://www1.va.gov/health/index.asp)

Veterans Benefits Administration (VBA): [www.vba.va.gov](http://www.vba.va.gov)

Vet Centers: [www.vetcenter.va.gov](http://www.vetcenter.va.gov)

VA Health Care Benefits/Information for Patients: [www1.va.gov/health/index.asp](http://www1.va.gov/health/index.asp)

VA Health Care Eligibility and Enrollment: [www.va.gov/healtheligibility/](http://www.va.gov/healtheligibility/)

Federal Benefits for Veterans, Dependents and Survivors: [www1.va.gov/OPA/vadocs/current\\_benefits.asp](http://www1.va.gov/OPA/vadocs/current_benefits.asp)

Environmental Agents Services (Service-Related Environmental Issues): [www.va.gov/environmentagents](http://www.va.gov/environmentagents)

Compensation and Pension Benefits: [www.vba.va.gov/bln/21/index.htm](http://www.vba.va.gov/bln/21/index.htm)

Returning Service Members – Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF): [www.oefoif.va.gov](http://www.oefoif.va.gov) and [www.seamlesstransition.va.gov](http://www.seamlesstransition.va.gov)

Center for Women Veterans: [www1.va.gov/womenvet/](http://www1.va.gov/womenvet/)

Women Veterans Health Care (Office of Public Health and Environmental Hazards): [www.publichealth.va.gov/womenshealth](http://www.publichealth.va.gov/womenshealth)



# Veterans Benefit from Peer Support

by Erin Kelly

Veterans of the U.S. Armed Forces have access to a vast network of medical care through the Veterans Health Administration, which is part of Veterans Affairs (VA). But it was only recently that the VA opened its doors to peer support groups like those the ACPA maintains. For military people it's sometimes easiest to find peers among fellow vets.

John Yeoman, a veteran and ACPA facilitator in Seattle, Washington, says that veterans often have a different perspective on pain than non-veterans do. "In the military, pain is seen as a normal thing," he explains. "In training, it's 'no pain no gain'" he says. "Pain keeps you safe and lets you know you're alive. You're thankful for it."



*In the service, there's a certain level of honor in pain.*

When Yeoman was injured on duty and developed chronic pain, his training told him to ignore it instead of trying to do less. "I wasn't prepared to take care of myself and let myself heal," he says. Yeoman also says that pain can be like a battle scar, something to be proud of. "There's a certain level of honor in pain."

Yeoman has worked with both civilian and veterans' ACPA groups since he got involved with the ACPA in the late 1990s, and says that military people seem to suffer a more drastic loss of identity if they become disabled.

"In the military, people are built up to feel like they're Superman," he says, noting that a sense of competence and self-reliance is essential to their jobs. "Then the next day they can't even walk because they've lost a leg or have a body

full of shrapnel. The ego comes crashing down—it's very hard to watch."

## **Veterans are Motivated to Overcome Disabilities**

Moving from military service to civilian life can be difficult for anyone, but it's even more challenging for veterans who leave active duty because of a disability. "We have people who are actually the best in the world at what they do and then they suddenly find themselves in the civilian world facing challenges to basic abilities—having trouble climbing steps, or driving a car, or providing for their families," Yeoman says.

But military training also equips veterans to take charge of their health and become their own advocates. "The determination and motivation level of veterans is just extraordinary," says Yeoman. "Their knowledge and training

gives them the ability to overcome adversity." Anyone who's been through basic training is familiar with hard exercise and understands its benefits—a plus when trying to stick to a physical therapy routine. "Some problems aren't solved by a pill," Yeoman says. "We're willing to do the work."

Yeoman says that veterans need to reconnect with the high self-esteem they had as active servicemembers in order to become their own advocates. "If they can find that self-confidence again, and find their voices, they become better able to take charge of their health," he says.

Even if a recovering ego means more friction with doctors, "it means they have a healthy fight in them," he adds. "When you reconnect with your self worth, regardless of your current physical ability, it makes you less vulnerable to depression, anxiety, frustration, and anger."

## **Young and Old Have Common Needs**

The people Yeoman works with in his VA-based and civilian groups are diverse in their ages and experiences. But recent military action has led to an increased number of combat-related injuries among relatively young people. Yeoman estimates he's been involved with about 15 groups; he currently facilitates one veterans' ACPA group and one civilian group. He is helping develop leaders for several new VA-based ACPA groups, and also teaches chronic pain advocacy at a local college.

Yeoman says that working with young veterans is rewarding because he can help make sure they have resources that he did not have when he left the Navy with chronic pain. "I'm doing things for people coming out of the military now that were never done for

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## Veterans Benefit from Peer Support

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me,” explains Yeoman. “I don’t want them to end up in the situation I was in.”

Another veteran working to make sure others get the support they need is Roger Mai. Mai facilitates an ACPA group based in Milwaukee, Wisconsin that was the first ACPA group to be hosted at a VA facility and affiliated with the VA. He gives credit to Jill S. Klayman, Ph.D., a psychologist and pain specialist at the Zablocki VA Medical Center in Milwaukee. “Dr. Klayman is the reason we have ACPA groups in the VA,” says Mai. “She started the group and after a few years she asked us to take over.”

Mai is one of three facilitators for the group, together with Dave Bailey and Michael Hutchinson. “It works out well,” Mai says. “Even if one or two of the facilitators has a problem and can’t make it to the group, there’s always one of us there.” The facilitators and Dr. Klayman have done outreach presentations at health fairs and to a variety of organizations, and are currently working to establish a support group associated with Dryhootch, a veterans’ support organization outside of the VA system.

Although Mai’s group is based at the VA, it is independent from the medical system and follows ACPA rules about confidentiality. The same goes for veterans’ ACPA groups in other cities. “When we’re there, the door is shut and it’s our group,” explains Mai. “No doctors or therapists can come in unless we invite them, and what happens in that room stays in that room.”

Still, Mai admits that they have access to some VA facilities that other groups might not have. “We’ve done Wii bowling as one of our activities,” he says. They’ve also had presenters come in to teach exercises and yoga—even adapting the moves for people in wheelchairs.



a helicopter crash over Thailand during the Vietnam War. “Officially, we ‘weren’t there,” Mai explains. Because the man’s work wasn’t part of an open record, the VA couldn’t verify that he was injured on duty. It wasn’t until the records were unsealed, decades later, that the veteran was able to receive VA benefits for problems related to that injury.

And veterans frequently have specialized information to help their peers navigate the VA benefits system. Mai says, “They need to understand what they’re entitled to.”

## We’re willing to do the work.

Mai’s diverse group includes several veterans who are dealing with long-term consequences of traumatic injuries they suffered decades ago. “Some of us are getting older and we never know what’s going to happen tomorrow,” he says. “If you get up in the morning and don’t have any new problems, you call it good.”

### Impact of Injuries Changes Over Time

Mai’s chronic pain stems from injuries he suffered in the line of duty 45 years ago. “My other injuries were so massive that I didn’t realize I’d also hurt my neck until I got older,” he says. Over the years arthritis has developed in his stressed joints and lingering paralysis in one leg causes him to fall frequently. “All the problems I have now are somehow related to those original injuries,” explains Mai. For people like him, he says “the impact of these injuries gets worse every year.”

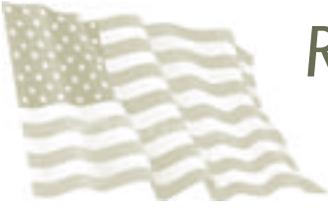
Like other ACPA groups, veterans’ groups often find that frustration with the health care system is a common topic of conversation—but the problems are sometimes a bit different. Mai tells the story of a friend who was injured in

Other frustrations are political. The turning point in Yeoman’s life came when he and his family moved from Colorado to Washington state so that he could attend a multidisciplinary pain program at a Seattle VA health center—a program doesn’t exist any more because of budget cuts.

“Don’t get me wrong, we get some great health care, but some therapies that could make a big difference in people’s lives can be cut because they lose funding,” says Yeoman. He would love to see the military and the VA expand access to peer support groups and provide more counseling for veterans’ families. “We could keep people healthier by supporting the whole family,” he says.

For now, both Yeoman and Mai are hopeful that their work—and the work of others like them—will bring much needed support to veterans of all ages and experiences. “I was really encouraged when I was invited to Pittsburgh for an ACPA facilitator training meeting and learned that there are lots of new VA groups starting up,” says Mai. “People need a place where they can go and just air things out with fellow veterans. That’s one thing we all have in common.”

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# Resources for Veterans: What to Expect When Filing Your Claim

by Jani Larsen

I always suggest to the veterans in my ACPA support groups that they do a little research before they file a claim for disability. By doing so, you may help your claim be processed quicker and you can estimate chances of getting disability benefits based on the results that others with your condition(s) achieved.

Look at other claims as guidelines to learn the process. See if they may have mentioned something you did not consider. Do not copy anyone else's claim as your own! That would be unethical. Do not mention your research or findings specifically when you write your claim as that would be confusing to the reviewer.

Here are some online resources that can help you understand the claims process.

1. Start researching your claim here:  
<http://www.index.va.gov/search/va/bva.html>
2. Understanding the disability claims process:  
<http://www.vba.va.gov/bln/21/Topics/claims.htm>
3. Find a service organization to assist you with your claim:  
<http://www1.va.gov/vso/>
4. File an application online:  
<http://vabenefits.vba.va.gov/vonapp/main.asp>
5. Appealing VA Disability process:  
<http://helpdesk.vetsfirst.org/index.php?pg=kb.printer.friendly&sid=9>
6. Disability Claims Criteria:  
[http://www.vfvc.net/pages/va\\_disability\\_rating\\_criteria.htm](http://www.vfvc.net/pages/va_disability_rating_criteria.htm)

## What the VA Does After It Receives Your Claim

After the VA receives your Application for Compensation, it sends you a letter. The letter explains what the VA needs in order to help grant your claim. It states how the VA assists in getting records to support your claim. The letter may include forms for you to complete, such as medical releases. They help the VA obtain pertinent medical records from your doctor or hospital. You should try to complete and return all forms the VA sends within a month. Your claim can often be processed more quickly if you send a copy of your own medical records. This letter is often referred to as the Duty to Assist letter. (This information is from [www.hadit.com](http://www.hadit.com).)

## What Records the VA Obtains to Support Your Claim

The VA then attempts to get all the records relevant to your claimed medical conditions from the military, private hospitals or doctors, or any other place you tell them. The person who decides your claim (called a Rating Veterans Service Representative) may order a medical examination. This is

referred to as a compensation and pension exam. This examination is free of charge. It is extremely important that you report for your examination at the scheduled time to avoid delaying your claim.

## Be Actively Involved With Your Claim

No one else has as much interest in the outcome of your claim as you do. You are dealing with the government and even though recent changes in law favoring the veteran have been enacted (VCAA), it is still up to you to provide supportive evidence for your claim and become familiar with the rules and regulations the VA plays by.

## More Tips For Veterans on Filing Claims

1. **Get competent representation.** You do not have to stick with one Veterans Service Officer. Find one you feel comfortable with and work with him or her.
2. **Request copies of your military service files, including medical and personnel (SF-180).** Send another request for your awards and decorations and, lastly, if you need your DD-214 send another SF-180. (<http://www.archives.gov/st-louis/military-personnel/standard-form-180.html>)
3. **Request copies of medical files from private physicians** (under the Freedom of Information Act).
4. **Request a copy of your unit's history and lineage from your area's archive (SF-180).**
5. **Make a log of all information mailed to or from you.** Be sure to log the date you received letters or attach the envelope with a postmark to your document and keep copies of *everything*.
6. **If you are working with a Veteran's Service Officer (highly suggested), send everything through him or her.** You will have another link to information if you lose anything. They will also double check your information for things that may not belong or suggest things to add.
7. **<http://www.hadit.com> has a discussion forum, which is very active; use it as a way to communicate with others** who are going through this process.
8. **Follow all the guidelines and read everything on your documents and websites.** If you have information on a hard disk, please be sure to back it up.

Welcome home! Thank you for your service.

Jani Larsen is the National Veterans Coordinator for the American Chronic Pain Association. Facilitators and prospective group members should contact Jani through ACPA headquarters at 1-800-533-3231 or [ACPA@pacbell.net](mailto:ACPA@pacbell.net).

# ACPA in Partnership to Raise Awareness about Prescription Medicine Abuse

by Alison Conte, Chronicle Editor

Six million Americans abuse prescription drugs, more than the number of people who abuse cocaine, hallucinogens, ecstasy, inhalants, or heroin combined.

The problem of prescription drug abuse surpassing the use of most illegal “street drugs” is worrisome to people who have a legitimate need for pain medications, and is the focus of a new educational campaign involving the ACPA.

*When Good Medicines Become Bad Drugs*<sup>SM</sup> is an effort to share information about prescription medication abuse through educational tools in pharmacies and online at [www.GoodMedicinesBadDrugs.com](http://www.GoodMedicinesBadDrugs.com).

The American Chronic Pain Association has partnered with Cephalon, Inc. and the American Pharmacists Association (APhA) to encourage the safe use of prescription pain medicines. The centerpiece of the campaign is the ACPA Pharmacist CARE card, a graphics-based tool to support pharmacist-client communications.

“Pharmacists play a key role in educating the public about prescription medicines, and the expansion of this program provides hands-on resources to support those conversations with the goal of reducing prescription pain medicine abuse,” said Dr. Lesley Russell, chief medical officer at Cephalon.

## Medication Knowledge Vital

“People with pain deserve appropriate treatment for their conditions, including prescription pain medicines, but one of our goals as an organization is to help people learn how to use them safely and correctly,” said Penney Cowan, executive director of ACPA. “We provide people with easy-to-understand information on prescription medicines, including how they should be taken and what things should be avoided, as well as safe storage and disposal.”

“This knowledge can be the difference between getting better and ending up sicker, even becoming a fatality,” said Penney. “That is why the CARE card’s easy-to-understand pictures are so helpful. It can also be a great aid to anyone who doesn’t read well, or speak the same language as their pharmacist.”

According to the U.S. Drug Enforcement Administration (DEA), the opioid pain relievers that people with pain need to function—such as morphine, oxycodone, and fentanyl—are the most commonly abused prescription pain medicines. Since these drugs are regulated by the FDA and prescribed by a doctor, people may think that they are a safer way to get high than heroin or cocaine. But if used by others in a way that is not recommended, they can cause illness and death.

## Why You Should Care

Legitimate prescription drug users can be unintended suppliers to drug abusers.

“Seventy percent of people who abuse prescription drugs get them from a friend or family member,” said pharmacist Janet Engle. “People need to understand that they may inadvertently help drug abusers.”

Janet Engle, Pharm. D., Ph.D. (Hon), FAPhA is executive associate dean and professor and head, Department of Pharmacy Practice, at the University of Illinois at Chicago College of Pharmacy.

“Offering your pills to a friend who is in pain is drug misuse,” Dr. Engle said. “By giving them drugs to relieve their pain, you may be masking an injury and delaying a necessary visit to the doctor.”

Taking any drug that is not specifically supplied for you, at the right time, in the right dose, is drug misuse, and can result in a dangerous drug interaction or overdose.

One of the current issues that Dr. Engle and her colleagues are discussing is double dosing of acetaminophen (Tylenol), which is also an ingredient in Vicodin and can cause liver failure if you take too much.

If drug abuse continues to increase, federal regulators may respond to these crimes by making it more complicated to fill prescriptions, requiring more red tape, raising prices, and restricting access for legitimate users to fewer pharmacies.

“Prescription medicine abuse is a growing concern in our country, so we need to use every available channel to communicate about safe use. As pharmacists, we promote public understanding of risks and benefits of prescription medications,” said Thomas E. Menighan, BSPharm, MBA, SCD, executive vice president and CEO of the American Pharmacists Association.

“You have a chance to consult a pharmacist whenever you get a new prescription. Pharmacists are the experts when it comes to drugs and have a broad range of knowledge,” Dr. Engle said. “A pharmacist will consider how the prescription will interact with over-the-counter drugs, vitamins, herbal remedies, even foods, drinks, and lifestyles.”

Dr. Engle also suggested:

- \* Use caution when going to the drug store. Be aware of who is around you and speak quietly to your pharmacist.
- \* Don’t talk about your medications in public, particularly if you carry them with you.



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- \* Dispose of drugs that are past their expiration date. They may be ineffective or dangerous.
- \* Always carry medications in their original containers, so they can be identified.
- \* Do not store them in a humid, bathroom medicine cabinet or the car's glove compartment. Consider a locked cabinet.
- \* Count your pills so you know if you are losing pills.
- \* Dispose of medications correctly, by mixing them with unappetizing materials, like cat litter or coffee grounds. Opioids should be flushed down the toilet.
- \* Always turn on the lights at night when getting medicines for yourself or your children, so you see what you are taking.

The website [www.GoodMedicinesBadDrugs.com](http://www.GoodMedicinesBadDrugs.com) also has advice for you if you suspect someone you know is abusing drugs, what signs to look for, and how to deal with it.

**Cephalon is one of the world's fastest-growing biopharmaceutical companies and sells more than 150 products in nearly 100 countries. (<http://www.cephalon.com>)**

The **American Pharmacists Association**, founded in 1852 as the American Pharmaceutical Association, represents more than 62,000 practicing pharmacists, pharmaceutical scientists, student pharmacists, pharmacy technicians, and others interested in advancing the profession.

See these back issues of *The Chronicle* online for more information about medication safety:

- [REMS: Fighting Drug Abuse or Limiting Access, June 2010](#)
- [Psychological Addiction with Opioid Use, March 2010](#)
- [Avoiding Drug Interactions, December 2009](#)
- [Proper Disposal of Prescription Drugs, June 2009](#)
- [The Myths and Truths of Medication, March 2009](#)
- [Your Role in Medications Safety, Winter 2008](#)

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## Lest we forget . . .

CONTINUED FROM PAGE 1...

It is because of these calls that we have been working to do more for veterans. We now have a National Veterans Coordinator, Jani Larsen, herself a veteran, whose focus is to support veterans' groups and direct them to a wealth of resources. The ACPA will be adding more resources focused on the needs of veterans to our website. We will share stories from several veterans whose involvement in ACPA has let them journey from patient to person.

Recently, we have reached out to veterans in Seattle and Anchorage to help them establish and conduct ACPA group meetings. We know that peer support is vital, that it can offer strength from other people who understand the challenges that pain creates in everyday life. We need to communicate to all veterans that it is possible to live a good life, despite the pain. Achieving this lifestyle, taking the journey, requires a personal commitment, but it is easier when supported by fellow veterans who have been down the road before.

The ACPA will continue its efforts to help each veteran with pain move from a patient to a person. We hope that you will enjoy this issue. It comes with our heart-felt thanks to each one of you.

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## Memorial

### STEPHEN SIBLEY

*Stephen Sibley, facilitator in Santa Cruz, California, died October 29 in a terrible automobile accident. We will always remember Steve and his compassion.*



*Born in 1947, Stephen Sibley moved to the Bay Area with his family, including two sisters, at age 11. Stephen and his brother Bob attended Saratoga High School and often surfed at Four Mile Beach and Pleasure Point when they were teens.*

*Steve started a support group with the American Chronic Pain Association in April of 1994. Steve suffered daily with chronic pain for many years. When he found the ACPA he was compelled to start a group to help others begin to have a better quality of life.*

*Steve was a very active leader in his community. His gift was empathy with people who suffered chronic pain. An extremely intelligent man, Steve once worked for Lockheed Space Program in Sunnyvale, CA with high security clearances. He volunteered with many organizations around Santa Cruz, not just ACPA, sharing his compassion with all.*

# Advance Planning Can Ease Holiday Travel

by Linda Winkler Garvin, R.N., M.S.N

Traveling over the holidays can be stressful for anyone, with tight security and the large number of travelers going to visit family and friends. It is important for people who are on a medication regimen or managing chronic pain to proactively plan for a satisfying trip and to be prepared in case things go awry.

## Before Your Trip

Many people rush around getting ready for their trip only a couple of days beforehand. It is much better to give yourself extra time and begin packing well in advance, so you can maintain your normal routine.

Also, make sure you maintain healthy habits at least four weeks prior to your trip. Keep yourself in good shape by eating fruits and vegetables, avoiding overly processed and high-sugar foods, getting exercise, and sleeping seven to eight hours per night.

If you are traveling with another person sit down with your travel companion and make sure they understand how many activities and tours you can do in a day without overdoing it. Are they able to give you time to rest, turn in early, stop and eat, or change plans so you can manage your pain? Come to an agreement on your strategy: will they proceed without you or wait until you are able to resume activities?

## Be Prepared

Your "Preparedness Bag" is similar to a first aid bag and should be part of your carry-on luggage. Never let this bag out of your sight. It should contain:

- \* Phone numbers and emails of friends, neighbors, medical providers, and emergency contacts.
- \* Cell phone (international cell if going out of the country), paper, and pen. This phone can be saved, if you desire, for emergencies or to decrease costs.
- \* Prescription medication you take on a daily basis, along with multivitamins, and vitamin C. Consider bringing over-the-counter medicines for problems with digestion, diarrhea, pain, allergies, and motion sickness, as well as antibiotic ointment and band aids. Don't forget insect repellent, sunscreen, and hydrocortisone ointment for insect bites if these apply in your destination.
- \* All medications including prescription and non-prescription in their original containers.
- \* An extra pair of glasses, hearing aids, and batteries. Take syringes if needed for diabetes management.
- \* Hand sanitizing solutions or individual sanitary towelettes (containing at least 60% alcohol) that are very handy before eating and for wiping the surfaces in airplanes, cars, and in bathrooms.

## Identification Card

You should also carry basic health information on a card that others can find should you become sick and are unable to remember or communicate.

- \* Your name, address, and birth date
- \* Insurance information
- \* Blood type
- \* Drug and other allergies
- \* Medications you take
- \* Primary medical problems including any medical events, surgeries, or hospitalizations that could be significant if you're injured or sick.

You can record this information on the ACPA MedCard, which is free to members or available for purchase on the ACPA website. It is also printed in the Winter 2006 ACPA *Chronicle*.

## On a Plane, Train, Bus, or Car

Airline delays and traffic incidents can cause you to miss scheduled meal times. Stay energized by bringing peeled, prepared snacks of fruits and vegetables like bananas, grapes, apples, pears, peaches, plums, baby carrots, or snap peas. Put some good-tasting cereal, nuts, and raisins in a sandwich bag. Try to stay very hydrated by drinking bottled water.

If driving, stretch your legs every one to two hours by pulling over at a rest stop and walking around. On a plane, stand up at your seat or walk in the aisle if you can. If you must remain seated, you can stretch your legs by extending your legs and flexing and pointing your toes about six times on each side.

To help prevent blood clots, don't wear tight clothing (especially around your legs and calves), since this can impede your circulation. If you have specific health concerns, ask your doctor what he or she recommends to prevent blood clots.

## Conserve Your Energy

Avoid carrying and pulling heavy baggage through the airport. Check most of your bags and carry only what you will absolutely need during your flight, including your preparedness bag. If your medical condition requires it, you can contact the airline ahead of time and request a bulkhead aisle seat (the first seat in coach) for extra leg room.

For efficient, energy saving travel, try to get a non-stop flight. Get your ticket and boarding pass ahead of time.

To minimize the amount of walking in the airport, request a wheelchair (even if you normally do not use one). Let them know if an attendant is needed to push it. This will help you save your strength and prevent pain flare-ups. This is

*The best of holidays  
to you and yours from  
all of us at ACPA!*



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particularly helpful when you need to change planes with little time to spare. **Anyone can request a ride from the electric cart. Get a handicapped parking permit to save steps in large parking lots.**

If you have your own wheelchair, contact the airlines to check on their individual procedures. It is important to utilize only “gel type cell batteries,” since many airlines may refuse wet cell batteries on their plane, due to possible dangers associated with them. Always put a permanent type of identification tag on your wheelchair. If you check your wheelchair with the luggage, verify with the airline attendant to make sure it was loaded on the airplane.

At your hotel, if you want to limit your walking, request a hotel room near the first floor and not too far from the elevator. This will decrease the distance you will have to carry your luggage and save you some energy.

It is important to be realistic about how much activity you can handle each day. Don't overbook yourself or schedule sightseeing trips for the day you arrive. Many people experience lethargy when they first arrive at their destination and it can take several hours or a couple of days for our bodies to readjust.

A simple walk, having a healthy meal or snack in a relaxed café or restaurant, or taking a nap may be an ideal way to spend your first day. Although you may want to see as much as possible, it is important to build in rest periods each day. You will be happier seeing less and feeling well than trying to see too much and suffering as a result.

This also applies if you are visiting family; rest up before tackling a large family dinner or party.

### **Avoiding Stomach Problems**

Poor hygiene practices in restaurants and pathogens in food bring on travelers' diarrhea for many vacationers. The CDC states that this is the most predictable travel-related illness and affects from 30% to 70% of travelers, depending on the destination. If you are traveling to any high-risk areas, check with the CDC and your physician to see if prophylactic antibiotics are recommended. In addition, if you are immunosuppressed, your physician may want you to take a short-term dose of a prophylactic antibiotic.

If you are travelling to a high-risk area, you can minimize this risk by eating only food that is freshly cooked and served very hot. These are safer than foods that may have been sitting for some time in a kitchen or in a buffet at room temperature. Risky foods include raw or undercooked meat, seafood, and unpeeled raw fruits and vegetables.

Use only beverages that are sealed or carbonated or otherwise known to be purified. This applies for brushing teeth too. Don't use ice cubes to cool beverages in locations where public water may be contaminated.

Besides using caution with food and water, limit your alcohol use, and do not drink and drive. It is wise to familiarize yourself with the local laws and customs of the country you are visiting.

### **Returning Home**

Remember to practice healthy and safe behaviors after you return home from your vacation as well. Sometimes the strain of travel will cause pain to flare up after you return. If you are not feeling well, make an appointment with your physician. Always mention where you travelled, for how long, and your food and beverage history.

The State Department website <http://travel.state.gov/> has helpful safety information about the countries you will visit.

The State Department's Bureau of Consular Affairs has an Office of Overseas Citizen Services that can be reached at 1-888-407-4747 from the U.S. or Canada. If calling from overseas, the contact number is 202-501-4444. For current recommendations on staying healthy while traveling visit these websites:

<http://wwwnc.cdc.gov/travel/>

<http://wwwnc.cdc.gov/travel/content/health-status.aspx>

Linda Winkler Garvin, R.N., M.S.N., of Alameda, California, is a Health Advocate/Consultant & Educator in the Bay Area and Director of Health Management Associates. Linda has expertise in chronic pain management, elder care planning & health advocacy. She is the author of several articles on pain management, healthy lifestyles, nutrition, and travel. Learn more at [www.healthmanagerbayarea.com](http://www.healthmanagerbayarea.com) or e-mail at [garvin\\_linda@yahoo.com](mailto:garvin_linda@yahoo.com).

# Understanding Fibromyalgia



Fibromyalgia is diagnosed when there is a three-month history of widespread pain in at least 11 of 18 trigger points. It affects more than 5 million Americans, predominantly women.

Along with chronic widespread muscle pain, people with fibromyalgia experience memory and concentration difficulties, lack of energy, poor sleep, fatigue, and depression. They have difficulty in obtaining a diagnosis, and also have trouble getting professionals to believe that they have pain.

Research indicates that the brains of people with fibromyalgia experience pain symptoms differently, and that diagnosis may be shifting from the area of rheumatology (muscles) to neurology (central nervous system) and anesthesiology.

Penney Cowan, ACPA founder and executive director, presented “Understanding Fibromyalgia” in Pittsburgh, Detroit, Portland, Oregon, and Ft. Worth, Texas. Here are some of the key points of Penney’s talk, which included references to her personal experience with fibromyalgia.

## Getting Treatment

Be cautious of any fibromyalgia treatment center that is expensive but does not feature treatment that has been shown effective by studies in reputable publications. Instead, ask a reliable physician that you trust for a referral to professionals. The new medications for fibromyalgia—serotonin and norepinephrine reuptake inhibitors (SNRIs) such as Cymbalta, Lyrica, and Savella—are tools, not a cure. They can be helpful in making you feel less pain, more in control, and more able to function.

While no herbal remedies have been shown to be effective, some people benefit from acupuncture, progressive relaxation, biofeedback, and good nutrition.

A new ACPA tool, the “Fibro Log” (<http://www.theacpa.org/fibrolog/fibrolog.aspx>), lets people with fibromyalgia track their pain, everyday activities, and feelings. This can help you and your health care provider better understand how different activities and circumstances may affect your pain.

## Learning to Live with It

- \* Fear of pain is a controlling factor that can limit quality of life even more than the pain itself.
- \* Depression doesn’t cause pain, but it is part of the long-term pain problem.
- \* Concentrating on the pain increases one’s sense of suffering. Reduce your sense of suffering and improve your quality of life.
- \* Pain is inevitable, but misery is an option.
- \* There may be a certain level of pain you will have to live with, but you can live a full life despite the pain.

- \* ACPA always accepts that when you say you have pain, you do. We also know that you are much more than a person with pain.
- \* Make the journey from patient to person. Your old life is gone, but you can reclaim the life that belongs to you.
- \* You are not alone. Join a support group to put pain in perspective, learn coping skills, and reach out to others.

The Living with Fibromyalgia video is available through the ACPA website ([www.theacpa.org/videoPlayer.aspx?gid=livingFibro](http://www.theacpa.org/videoPlayer.aspx?gid=livingFibro)). The “Understanding Fibromyalgia” program is sponsored by Pfizer Inc.

# Memorial

## JANE COLBORN

Jane Colborn, former secretary to the board of the ACPA, passed away on September 1, 2010 at the age of 91. She was interviewed for the 30th anniversary edition of The Chronicle.

“Jane was a devoted friend to ACPA and to those of us who worked with it during the early years,” said Dr. Edward Covington. “She was generous with her skills and her compassion for those in pain. I thought she was a wonderful lady and that we were blessed to have her on our team. Her passing is a loss.”

“I don’t think that words can express the contribution that Jane made to the ACPA,” said Penney Cowan. “Jane provided a significant amount of expertise, time, and effort in helping us write the by-laws that are still used today with only a few amendments. Jane was by far one of the nicest people you will ever meet. Her interests were always in helping others. I can still remember her wonderful laugh. She will be deeply missed but has left a wonderful and lasting memory for all of us who were honored to know her.”

Her nephew Kurt Colborn remembers that Jane gave of herself to many organizations. “But what I know of her experience in all those capacities is not so much what she did, but who she met and befriended while she did it. Jane definitely lived with purpose, so we might remember her for her never ending zest for life.”

# ACPA Updates

## ***New Board Officers Elected***

Andrew Bertagnoli, Ph.D., senior consultant in behavioral medicine and pain management at the Care Management Institute of Kaiser Permanente in Oakland, California, was elected president elect at the [ACPA Board of Directors](#) meeting on October 9. Andrew will become president in 2012 when the term of our current president, David Provenzano, ends. Also holding offices for 2011 are Daniel Galia, treasurer, and Joanne Schneider, secretary.

## ***ACPA Develops Opioid Safety PSA***

Deaths from the misuse or abuse of opioids are at an all-time high. Yet these medications can be a valuable tool in keeping pain under control. To call attention to the importance of safe use, storage, and disposal of opioids, the ACPA has developed a public service announcement, with funding support from King Pharmaceuticals. Preview it on our website at [www.theacpa.org](http://www.theacpa.org).

The announcement is running in theaters in the Sacramento area and in West Virginia. We hope to get additional funding for wider distribution in 2011.

## ***Alaska Vets Learn Pain Management Skills***

Penney Cowan, ACPA founder and executive director, visited veterans' hospitals in Alaska this summer and fall to introduce health care professionals and veterans to the basics of pain management. Out of these talks, in Fairbanks and Anchorage, several new ACPA groups have been established to provide ongoing support to former service men and women living in the state.

## ***Electronic Fibro Log Now Live***

The ACPA website ([www.theacpa.org](http://www.theacpa.org)) has a new resource for people living with fibromyalgia (FM). The new electronic [Fibro Log](#) allows you to sign in to our secure server with a password, record your status on the many aspects of your condition, and have the results stored and charted over time.

Your personal log can then be printed out to be shared with your health care provider or simply used to track your progress over time. This new resource was made possible through support from Pfizer.

Visit the [fibromyalgia](#) section of [Conditions A to Z](#) on our website for this and other new materials to help you have a better quality of life with FM.

## ***ACPA Survey Looks at Attitudes and Behaviors Regarding Opioid Medications***

Those who use opioids properly, under a prescriber's care, need to understand how to take, store, and dispose of their medications to keep themselves safe and keep their medications out of the hands of potential abusers. Yet a recent survey conducted by the ACPA indicates that relatively few of those receiving opioid prescriptions are given sufficient education about the drugs to ensure safe use. The study, underwritten by an unrestricted educational grant from Purdue Pharma, surveyed people via random dial who use opioids for pain management.

Of those surveyed, only 28% were asked to sign an opioid agreement. Opioid agreements explain the risks and responsibilities involved in using opioids. Among those asked to sign one, 10% received no counseling and 45% had less than 15 minutes to discuss the issues with the health care professional.

Diversion, the theft or resale of opioids for recreational use, is the most common way these drugs get into the hands of those for whom they are not intended. Yet just 14% of those surveyed keep their opioids in a lock box or other locked location. Nearly 25% store their medication in the medicine cabinet.

"Securing your medicines is the best way to avoid having them taken by casual visitors, workers, or even teens who don't understand the risks," said Penney Cowan. "Our study indicates that we still have much work to do to ensure that individuals who can benefit from opioids know how to take them, store them, and dispose of them properly. Even one unintentional death is one too many."

Penney and David Provenzano discussed the results in a radio media tour. Stations in 17 markets carried the interviews.

## ***Integrative Medicine Day is January 23***

The ACPA will participate in the second annual [International Integrative Medicine Day](#) on January 23, 2011. The event is sponsored by the American Medical Student Association (AMSA). Integrative medicine is an approach to medicine that emphasizes the importance of using all appropriate therapies: self-care, patient empowerment, addressing the whole person (body, mind, and spirit), and fostering a healthy lifestyle. The ACPA contributed a wellness kit for people living with chronic pain to the materials that will be distributed in support of the event.

# Thank You!

# Tributes

Welcome to our new groups and facilitators.

**Tammy Christensen**  
Napa, CA

**Elizabeth Mendoza**  
Bakersfield, CA

**Gary Hill**  
Roseville, CA

**Deborah Batey**  
Grand Rapids, MI

**Sue Breen**  
Oswego, NY

**Sandy Rozelman**  
Cleveland, OH

**Missy Oesterheld**  
Fredersburg, VA



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

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Thank you to these corporations for grants that enabled ACPA to fund special projects.

**Pfizer** for the fibromyalgia education campaign

**Medtronic and Purdue Pharma** for an unrestricted educational grant to develop the new ACPA website

**Forest Laboratories** for the fibromyalgia Web-based interactive person

**King** for support of the Consumer Guide

**Medtronic** for the Understanding Medical Devices Video

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.

IN MEMORY OF  
TRACY KERSLAKE  
MY SISTER, MY FRIEND

Given by Keith and Kristina Faller

IN MEMORY OF  
TRACY KERSLAKE

Given by Greg Skau

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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