American Chronic Pain Association

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CHRONICLE

Men Who Live with Pain

by Penney Cowan, Executive Director, ACPA

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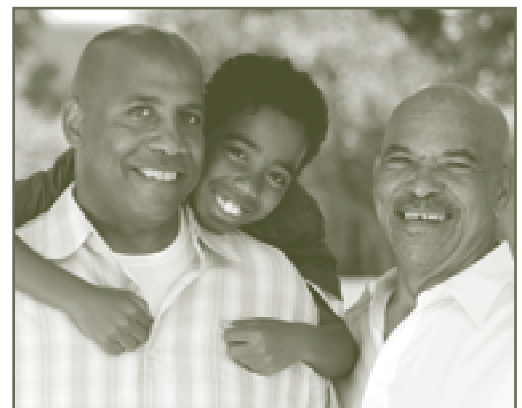
If you have your health you have everything, or at least that is how the saying goes. However, to maintain good health we need to be proactive, eat well, exercise, and have regular checkups and screenings.

Today, health awareness seems to focus on women's issues. We learn how important it is for a woman to develop a strong relationship with her health care provider. Breast cancer awareness is celebrated in October with pink ribbons, pink electric mixers, pink fountains, and walks for a cancer cure.

But what about men? What can we do to help a man pay more attention to his health?

There is a federal Office of Women's Health, but no Office of Men's Health. Men get breast cancer—approximately 1,700 new cases a year compared to 200,000 women—but still, the ribbons are pink, not pink and blue. Men get heart disease, prostate cancer, and chronic pain, yet the marketing for men's health is still aimed at the women who live with them.

It is not that men are less likely to get sick or hurt—in fact, they face more injury-causing situations than women. But how often do you see a nation-wide campaign encouraging men to pay attention to their health and well-being? Other than ads for ED treatments, it is rare that we see any reminders focused on men's health.



Medicine has come a long way in helping us to live fuller, happier, and healthier lives and both genders should benefit from this progress.

Strong and Healthy

Men have been portrayed as the strong, dependable, and healthy gender, right? Wrong, they are just as susceptible to disease and illness as women. It's just that they have been taught—since they were knee high to a grasshopper—that they need to shake off any pain and keep going.

"Big boys don't cry" is what a little tee ball player hears when he is injured, part of that different standard for recognizing pain and injury in boys vs. girls. So men grow up believing that complaining about their physical well-being is not the "manly thing to do." Men are the breadwinners, the family leader, the touchstone that everyone depends on.

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Why Big Boys Don't Cry

by Alison J. Conte

Men learn to ignore their pain early in life. When a five-year-old boy falls down, gets hurt, and cries, he is told to suck it up. He is told that "big boys don't cry."

"So when he is 50 years old, he will be apt to ignore the first signs of heart attack or stroke because he has been socialized not to talk about or react to pain," said Scott Williams, vice president of Men's Health Network (MHN). "Men tend to bury their pain, hurt, and the emotions that come with pain. They avoid meaningful discussions about health."

Williams said that men may even take pride in their pain, bragging about that old football injury that made them a big guy on campus, or a battle wound that created a war hero. The pain becomes part of a man's identity.

But buried emotions catch up with you. By age 50, men begin to suffer from a lot of health problems like heart disease, prostate disease, and high blood pressure. "They need to overcome their social upbringing before they can take ownership of their health. It's a lot to overcome," he said.

The Men's Health Network is committed to breaking down the social barriers that prevent men from discussing their health and encouraging men to participate in early detection and disease prevention. "Our motto is to build healthy families, one man at a time," Williams said.

When Men Let Their Guard Down

Williams has found that peer-on-peer networking works well to help support and educate men with pain. "In guy-to-guy conversations, men may let their guard down," he said. Work places, sports venues, and religious communities have proven to be good settings to answer men's questions about health.

Men tend not to read health journals or attend seminars. So to reach them, "We use the techie route, sporting events, or blue collar work settings to show men how to partner with their doctors to talk about pain and other health issues," Williams said.

Support groups work well for men with prostate cancer, but not so well for those with heart disease. "When it really impacts their lives, men will take part in local networks and groups," Williams said.

Men are more apt to have pain as a result of injury, workplace accident, sports, or military service. Years of hard, blue collar labor or exposure to dangerous work situations can cause pain.

MHN emphasizes the connection between depression, stress, anxiety, and increased pain.

Men worry about keeping their jobs and supporting their families, particularly in tough economic times. But when they are worrying about the pain's impact on their ability to do their jobs, work around the house, or enjoy hobbies, the stress of that very situation can make the pain worse.

Opening Up to Doctors

The Men's Health Network team has found that men are apt to dismiss their pain, even when talking to their doctors. As Williams said, "We know that women are more likely to see their doctors annually, but men aren't as

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comfortable with an annual exam or asking their doctor to 'take a look under the hood.'"

So MHN advises doctors to take more time with men, to ask a couple of extra questions about their personal lives. These non-health conversations will lead to discussions of health issues.

"Men are not apt to have preventive tests. They go to their doctor when they want something fixed," Williams said. "Often erectile dysfunction will be the issue that brings men to the doctor. Then the physician will discover that high blood pressure, diabetes, or high cholesterol is the underlying cause of the problem."

MHN also educates men on the warning signs of heart disease, stroke, and osteoporosis. "Because they don't get bone density tests, they don't find out they have osteoporosis until they have a fracture," Williams said. "Men don't want to admit that pain is an indication of a health problem. By not talking about or admitting to their pain, men are missing the first step on the road to better health."

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Men's Health Network is a national non-profit organization whose mission is to reach men and their families where they live, work, play, and pray with health prevention messages and tools, screening programs, educational materials, advocacy opportunities, and patient navigation.

Resources for men and their families from Men's Health Network include:

Blueprint for Men's Health: A Comprehensive Guide to Living a Healthy Lifestyle: **www.blueprintformenshealth.com**

Your Head: An Owners Manual to Understanding and Overcoming Depression, Anxiety, and Stress: **www.blueprintformenshealth.com/ownersmanual**

Get It Checked: A Schedule of Checkups and Age-appropriate Screenings for Men and Women: **www.menshealthnetwork.org/library/pdfs/GetItChecked.pdf**

Men's Health Library: **www.menshealthnetwork.org/php/library.php**

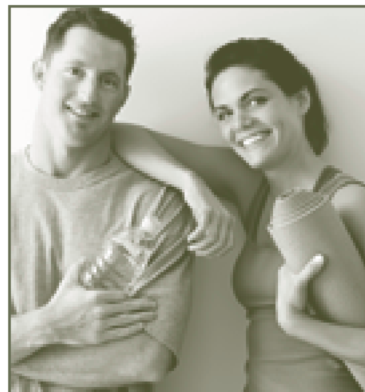
WEAR BLUE: Support Men's Health Education, Awareness, and Outreach: **www.menshealthnetwork.org/wearblue**

To get involved or join Men's Health Network please contact:

Men's Health Network
PO Box 75972
Washington, DC 20013
Office: 202-543-6461 ext. 101

www.menshealthnetwork.org

In guy-to-guy conversations, men may let their guard down.



A Minority of Men: The Masculine View of Chronic Pain

by Erin Kelly

For a man with chronic pain, finding a way to talk about it isn't easy. Even if he overcomes the social barriers, finds a support group, and gets up the courage (and energy) to go to a meeting, he may often be the only man in a room full of women.

It's a scenario that can be uncomfortable, and make it hard for him to share his feelings, despite everyone's good intentions. Although men are rarely considered a minority population and are just as susceptible as women to chronic pain, men make up a small percentage of support group participants.

To understand why, we talked with two ACPA facilitators about some of the issues that men find especially challenging when living with chronic pain.

Support Group Dynamics

Many men feel there is a stigma associated with going to a support group or counselor. "I've been the group leader for two or three groups, and if I'm lucky, one or two men will come," says Tom Norris, an ACPA facilitator in the Los Angeles area. "In one group, I never did have a second man."

Ernie Merritt, an ACPA facilitator in Maine, says things are no different on the East Coast. "In the last couple of years there have been more men, but still only one or two at a time. It's mostly women who come to the groups," he says. "Men aren't supposed to cry in public," Merritt points out, "and that does sometimes happen at the group."

Without a gender mix, men can be reluctant to participate in a support group discussion. But when another man is there, they will both be more comfortable talking about their own limitations. "In a group with only one man, men tend to sit back and listen," says Merritt. "If there are two men, they'll talk—the conversation goes back and forth a lot easier," he says. "I think maybe they don't want to seem like 'less of a man' in front of women."

Women also benefit from a mixed group. "I think the group works better when there are both male and female participants," says Merritt. "Men and women look at life differently, so [with a mixed group] we get different perspectives. We even joke about 'the man thing,'" he says.

Norris says that men can learn from women's examples as well. "Women seem to be better at accepting pain and realizing that all they can do is do their best," Norris says. "They're better at modifying their lives."

Pushing For a "Cure"

It may be a gender stereotype, but very often if you tell a woman your problem she will sympathize, while a man will try to solve it. So while all people with chronic pain have trouble admitting that there is no "magic bullet" solution, men sometimes feel this more strongly than women do.

Men and women look at life differently.

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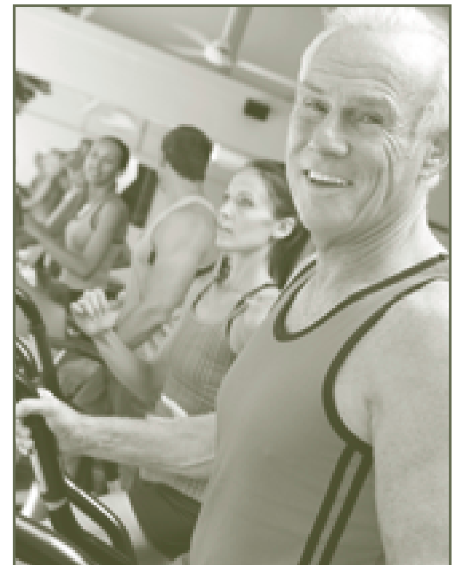

It's considered less than manly to show pain.

Norris tells a story of a man with phantom limb pain who kept seeking out more and more extreme medical treatments. "He kept looking for a cure that doesn't exist, instead of focusing on what he could do to improve his life every day," Norris says.

Merritt has personally struggled with the ambiguity of having chronic pain. "I tend to think of things as black or white—you either have a disease or you don't," he says. "I'm used to focusing on one thing at a time and getting it resolved—unlike my wife, who can handle all kinds of different things at once," Merritt says.

Chronic pain did not fit Merritt's medical model of symptom, diagnosis, and cure. Even after he started attending a support group, Merritt was not convinced he had chronic pain. "I thought, 'Yeah, I have pain, but it's better than it used to be,' " he explains. "Eventually I realized that you don't have to be at a '10' every day to have chronic pain. That's when I started to make my own plan for getting better."

It's Okay to Show Pain

For Norris, helping other men was part of the reason he started speaking openly about his pain. Norris traces his spinal pain to radiation treatments he had for testicular cancer in 1985. Unlike some men, he says, "I never had a problem with going to the doctor. I was raised by a nurse and took pre-med courses in college."

He says the medical care he received was excellent. But when his pain lingered and doctors told him his test results were "normal" he decided to stop talking about his pain.

He credits his wife Marianne with helping him realize that he deserved answers about why he was hurting. He also realized that he could help other people facing the same treatment. "If I don't talk about what's wrong, other men will be ignorant about what could happen to them," he says.

One reason men tend to delay acknowledging their pain is that they are afraid of losing status as a tough guy. "It's considered less than manly to show pain," says Norris. "Men are taught that they should be able to handle it."

Norris was in the U.S. military—an environment where toughness is the rule—when his pain started. "I was a lieutenant colonel in the Air Force with 2,000 people working for me," Norris says. "I thought that people would lose respect for me if I showed my pain." But Norris found out he was wrong.

"I was working with a two-star general," Norris explains, "and one day he saw me try to run. I could barely walk because of the pain. He pulled me into his office and asked me what was wrong. After I told him, he pushed me to take action," Norris says.

"I think it's a sign of maturity to accept that someone else has pain and help him to do the best he can," Norris adds. "Some men have trouble letting go of the idea that men should be able to tolerate pain… I think it's just lack of experience," he says. "Even some doctors have that problem."

Merritt agrees, saying, "My father never talked about being sick or hurt, and he never went to the doctor. I figured men don't do that." Merritt always believed in, "No pain, no gain," until he got so sick he couldn't believe that anymore.

This often happens among men with pain. Merritt knows a man who refuses to change his daily routine—which includes walking long distances—despite the fact that he could have less pain if avoided this activity that triggers his pain.

"It feels like you're giving something up," Merritt explains, "But if you keep pushing yourself for too long, you're going to break down." Instead, Merritt encourages people to learn to understand their own pain (as ACPA recommends).

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A Minority of Men CONTINUED FROM PAGE 5...

"Pain is a signal from your body," he says. "It's telling you there's something wrong. If you pay attention, you can figure out what it's telling you. If you keep track of your pain, and one day your pain moves to a different part of your body or gets worse, maybe you can figure out what you did the day before to cause that to happen."

Finding Self-Worth after a Career Loss

Another issue that hits men harder than women is the fear of losing their jobs because of pain. Although women are also troubled about being unable to work or care for their families, men frequently base their identity and feelings of self-worth on their career success.

"Some men think that if they can't do their job, they're not good for anything," says Norris. Similarly, Merritt grew up believing men were supposed to be the family breadwinners and that a day when you didn't produce something was a wasted day.

Both Norris and Merritt eventually had to leave their full-time jobs because of pain and find their own ways to feel worthy.

Norris created his own jobs after his medical discharge from the Air Force. "I had to find a job based on what I could do," he says. "I developed an after-school program that served about 55 kids in my neighborhood," he says. "I was useful, and doing a service for my community—it kept my ego healthy."

Today, Norris volunteers several hours a day at his church and is still finding other ways to be useful with the skills he has. He says that his wife and his faith have helped him believe that he has a lot to offer the world even if he does not work a full-time job. "Pain does not decrease your value as a person," he says. "I think men have a hard time understanding that."

Merritt advises people with pain to focus on small accomplishments and use smart strategies to achieve their goals. "Pick something each day to do," he says. It could be a household chore or a hobby project, or just a daily activity that is sometimes difficult.

"Break it up into smaller tasks. You might have to divide it up into chunks of time to avoid sitting in one position or standing too long. It might take all day, but you can accomplish something every day."

If the large task seems overwhelming, focus on the individual steps and pace yourself, Merritt says, adding that he gains a lot of self-esteem from focusing on daily accomplishments.

"I tell people, 'Don't give up. You can still do jobs around the house, you just have to be creative about how you do them,' " he says.

Finding New Social Networks

A real problem men face when they have to reduce their daily activities or lose their jobs because of pain is the loss of social support.

Men socialize with their work colleagues, but if they leave their jobs, those relationships end. Other relationships—and conversational topics—involve active hobbies like sports and home improvement. "It's the 'man thing' again," says Merritt. "We like to talk about tools. We like to show off the shiny new project we just finished." A less active man with chronic pain could feel out-of-place in these settings.

Pain does not decrease your value as a person.

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In addition to support from their wives and families, men living with pain can find new friendships by getting involved in volunteer projects and through groups like the ACPA. Merritt frequently calls a friend to go to their support group together—another way to make sure that he is not the only man in the group!

Hope for the Future

Both Norris and Merritt believe that things are changing for men. In recent years they've seen more and more men coming to support groups and speaking out about their struggles with pain. American culture has become more accepting of the idea that men can express their feelings and admit to pain without being considered weak.

The ACPA's philosophy of taking charge of your life while acknowledging your individual limitations fits well with these changing attitudes.

"Men might think they shouldn't show pain," says Norris. "The way the ACPA puts it is that you shouldn't exhibit 'pain behavior'," he says. ACPA affirms that you can acknowledge that you have pain but still have a positive attitude and control your own life. Merritt says that the ACPA's techniques can help men regain that feeling of control over their lives and health, a sense of control that is so important to them. "Through the ACPA, I found out that I have to be my own advocate," Merritt says. "It used to be that doctors were like gods; everyone went to one family doctor and you did what he said. Now I know that one doctor might not have all the answers, and I'm allowed to find another doctor or specialist if things don't work out." "Men are more open to talking about pain now," says Merritt. "The stereotypes are being changed."

Norris gives an example from his own life to show how attitudes are changing. "My father never acknowledged pain," Norris says, "And it killed him—he died suddenly from a heart attack. My mother had pain too, but she treated it and it never stopped her," Norris explains. "I'm not going to stop either."

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Men Who Live With Pain CONTINUED FROM PAGE 1...

With so much responsibility, how can a man be weak, leave work because of pain, or even take time out to take care of his health?

For these reasons, and in response to the many calls we receive from men seeking help for their pain, the ACPA is devoting this issue to men's health and men's response to chronic pain. We will explore some of the reasons why men do not listen to what their bodies are telling them. We will hear from Scott Williams, vice president of Men's Health Network, about issues that men face when it comes to their day-to-day health. Male ACPA facilitators will share their personal journeys from patient to person. We will learn how support groups can help men and how men can build better relationships and improve communications with their health care providers.

If men and women have different ways of approaching the world and that world includes chronic pain, they may differ in their responses. However, the one thing that is not different is that pain can consume the person with pain (man or woman) and the entire family.

How Men Experience and Manage Pain

by Gail C. Davis, RN, EdD, Professor Emerita, Texas Woman's University

In the Fall 2008 issue of The Chronicle, *we reported on research by Gail Davis to develop better ways to assess chronic pain. Through the ACPA Web site, we surveyed people with pain using two assessment tools that can also be used by medical professionals.*

The study revealed that using a variety of pain management methods—as practiced by ACPA and pain rehabilitation programs—is important. We are now revisiting these data to see if they might shed some light on how men and women are similar and different in how they experience and manage pain.

Assessing How We Live with Pain

As part of refining the *Chronic Pain Experience Instrument* (CPEI), it was linked to the ACPA Web site along with two other instruments:

* *The Pain Management Inventory* (PMI) is an inventory of pain management methods used and found to be helpful.
* *The Pain Management Outcomes Expectation Instrument* (PMOEI) is a measure of the confidence one has that the performance of a pain management method will have a positive outcome.

The major objective of the online study was the refinement of these tools to help us assess the experience of living with persistent pain. In all, 204 persons, 47 males and 157 females, responded to these instruments online. The original study (published in the ACPA *Chronicle*, Fall 2008) may also reveal how men and women respond to pain management methods.

Epidemiological studies show that pain is more prevalent in women, or at least that women seek medical treatment for pain more often than men do. The determination of a pain-related diagnosis may explain this phenomenon, as women more often experience the arthritis diagnoses of rheumatoid arthritis, osteoporosis, and fibromyalgia. These are conditions which have a long duration and it could be that duration is the factor most associated with the prevalence of pain.

Do Men Feel Less Pain?

Several studies have not been able to clearly show if pain intensity ratings are higher for men or women. Neither is it clear whether pain management and response to treatment are different between men and women. Limited studies suggest that women may respond better to the use of nonpharmacological cognitive-behavioral techniques.

Knowing the pain-related diagnosis is important when discussing how pain is managed. By just looking at the diagnoses self-reported by this sample, we see obvious differences related to gender. (Because the numbers of men and women responding were quite different, percentages rather than actual numbers are of interest.)

Fibromyalgia (FM) was identified as a diagnosis by 60 (38.2%) of the women and by only 7 (14.9%) of the men. On the other hand, generalized back pain and back injury were noted by 26 (55.3%) and 20 (42.6%) men and 59 (37.6%) and 28 (17.8%) women, respectively. Clearly, FM was a greater issue for women, while back pain represented a greater problem for men.

Respondents noted all of the diagnoses they had and only 62 (30%) had just one condition. An exploration of the data was done to determine whether the expected number of frequencies of three diagnostic categories (i.e., arthritis, back and neck pain, and neurological pain) were different than would be expected 50% of the time. Findings indicated that both men and women had a significantly higher number of back and neck pain diagnoses and a significantly lower number of neuropathic pain diagnoses than would be expected. No significant differences were found between the frequency and the expected number of arthritis diagnoses. Musculoskeletal pain was clearly the major issue for this sample.

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Men, generally, may be more proactive in handling their pain.

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Both Able to Manage Pain

When asked how well they were managing pain overall, there was no significant difference in the ratings: on a scale of 10, men reported a mean of 5.0, while women reported a mean of 5.38. In relation to this, though, women had a significantly higher rating of average pain intensity over the past week ($M = 8.06$) than did men ($M = 7.17$).

The scores on the CPEI were compared to determine whether the overall experience of living with persistent pain was significantly more positive for men than women. This experience is composed of three dimensions: interference with function, distress, and helplessness. Men did score higher, or more positively, on each of these and one dimension, helplessness, was significantly higher. This finding indicates that men, generally, may be more proactive in handling their pain.

Confidence in managing pain also seems important. Participants responded to the PMOEI, which provides a look at one's confidence in achieving desired pain management outcomes. Both gender groups scored essentially the same, indicating that their confidence level was moderate. Individuals responded to a list of 14 pain management methods in two ways—frequency of use and helpfulness. Each was rated on a scale of 1 to 6.

Each Approaches Pain Differently

An analysis of differences in use and helpfulness by gender revealed that the following methods were used significantly more often by women:

- massage ($p = .002$)
- heated pool, tub, or shower ($p = .03$)
- heat application ($p = .02$)
- focusing on religious beliefs ($p = .05$)

Methods rated as significantly more helpful by women were:

- massage ($p = .02$)
- heated pool, tub, or shower ($p = .04$)
- heat application ($p = .02$)

All of these methods represent more passive physical approaches to management.

While the differences by gender were not significant, methods used more often by men than women were:

- antidepressants
- bracing/splinting
- taking other prescribed medicines.

They found distraction, bracing/splinting, and self-talk to be more helpful than did women. Using a brace or splint can be explained by the more frequent diagnosis of back injury.

When asked to list methods that were most helpful, men gave these examples of distraction:

- Staying creative within my CURRENT limits
- Remembering passages about pain in the New Testament
- Focusing on entertainment, music, and TV
- Watching the History Channel

They provided few examples of self-talk, but we can infer that it is used from these positive-thinking statements: "acceptance and keeping a positive attitude about my pain" and "believing in my powerful inner will."

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How Men Manage and Experience Pain CONTINUED FROM PAGE 9...

Distraction, Pacing, and Medications

What do men use most often and find to be most helpful? To answer this question, the methods that were used or found to be helpful at a rating of 3 or above were identified. These may be seen in the accompanying table, listed in the order of their highest to lowest average rating. Prescribed medicines, pacing activities, and distraction techniques were in the top three for both "used" and "helpful."

Data on how men manage their pain do indicate that they may use more active approaches. Certainly, taking medicine as prescribed is important to the ongoing relief of pain and is recognized as a helpful strategy. But what about pain modulation methods that can be used as needed, alone or in combination with other methods?

Pacing activities, so as not to overdo and increase pain, was noted as a method used often and found to be helpful. Interestingly, when men were asked to identify in writing the methods that were most helpful, they were more likely to list "resting" and "lying down." Some indicated that lying down in a particular position was important. The implication seems to be that lying down and its related descriptions might be viewed as one aspect of pacing activities rather than simply "resting."

A More Positive Experience

Examination of these data do indicate that men rate pain intensity lower, have a more positive overall experience of living with persistent pain, and have a greater occurrence of back pain, especially related to back injury, as compared to women. It shows that:

- Both genders use a variety of pain management methods.
- Taking prescribed medicine is important to both groups, likely providing some pain relief.
- Using a variety of methods to modulate the pain over time is also important to both groups.
- The significant differences found between the genders may indicate that men are not as likely to use less active methods such as massage and heat. This needs further exploration.

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Perhaps men and women experiencing chronic pain should be treated differently by health care providers. If so, the differences should be based on specific patients' needs rather than purely on gender.

Men, in fact, may respond somewhat differently to pain than do women. More importantly, though, it seems that pain management needs to focus on the individual and the diagnosis or diagnostic category. Willingness to learn and use certain management methods may be related to gender, but may also be affected by other factors such as one's culture and personality (how open he or she is to exploring new approaches).

Some methods may be viewed as more helpful than others, but every person experiencing chronic pain needs to have a combination of methods available for use at any time.

Pain Management Methods Men Use and Find to be Helpful

MOST USED	RATING
Prescribed medicine	5.26
Distraction	4.55
Pacing activities	4.26
Antidepressant	3.91
Self-talk	3.51
Stress reduction	3.51
Heated pool, tub, or shower	3.50
Exercise	3.02
Heat application	3.00
MOST HELPFUL	**RATING**
Prescribed medicine	3.65
Pacing activities	3.29
Distraction	3.07
Heated pool, tub, or shower	3.07

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.

Give a Tribute During Pain Awareness Month

As those of us with chronic pain travel the hard journey from patient to person, one thing is clear: no one makes the journey alone. If you think about it, you will realize there are many people who have helped you.

- The doctor who treats your pain
- The therapist who pushes you to do more
- The nurse who listens
- Your ACPA support group members and facilitator
- Your spouse, patient and kind
- Co-workers who fill in when you can't be there
- Neighbors who lend a hand or just a smile
- Relatives who appreciate when you do what you can
- Friends who keep calling—despite the days you can't socialize
- The volunteers and aides who keep you going
- ACPA resources and personal support—there whenever you need it

So many people do so much; why not recognize them this September, during National Pain Awareness Month, with a tribute gift to the American Chronic Pain Association?

Your gift to ACPA during Pain Awareness Month will not only give you the opportunity to thank those who have helped you, but will also help ACPA to...

- Expand the ACPA support groups network
- Provide training to support group facilitators
- Develop more tools and educational materials on pain management
- Offer online resources though our Web site (averaging 700,000 hits a month)
- Expand public and professional awareness of chronic pain through outreach to healthcare providers, social service organizations, and the media.

Don't miss the opportunity during National Pain Awareness Month to recognize the special people in your life. At the same time you will help ACPA reach out to others who are in pain.

You can learn more about National Pain Awareness Month on page 12.

When your gift in honor is received, a personalized tribute note will be send to the person(s) or family you indicated. (The amount will be kept confidential.) All tribute gifts will be listed in a future issue of the ACPA *Chronicle*.

You may donate with a credit card online at **www.theacpa.org**. Or send this form and a check to **ACPA, P.O. Box 850, Rocklin, CA 95677.** The American Chronic Pain Association is a non-profit, tax-exempt 501(c) (3) organization. Donations are tax deductible.

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A Pain Awareness Month Tribute

My Name____

Street Address ____________________________________

City ______________________ State ______ Zip Code ____________

This gift of $________ is in tribute to ________________________(name)

for ______________________________(reason for the recognition)

Please send an acknowledgement to ____________________________

Street Address ____________________________________

City ______________________ State ______ Zip Code ____________

Thank You!

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

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September is National Pain Awareness Month

Raising Awareness and Encouraging Action

Eight years ago the ACPA started a project to declare September as a month to increase awareness of the impact of pain upon society. While much has been accomplished, we still need to bring this awareness to the attention of a wider public audience.

The year 2001 was marked by President Bill Clinton and the U.S. Congress declaring 2001 to 2010 to be the Decade of Pain Control and Research. Soon thereafter, the ACPA pulled 80 organizations into Partners for Understanding Pain (PUP), an informal coalition working together to designate September as Pain Awareness Month in all 50 U.S. states.

In September 2004, we held the Partners for Understanding Pain Summit with our new partners, forging a strong collaboration to focus on issues of pain. That year 18 states issued proclamations to declare September as Pain Awareness Month. Many scientific meetings and conferences about pain were held during September 2004 too.

In September 2005, PUP conducted a meeting to focus on disparities in care. Congressman Mike Rogers (R-Michigan) gave the keynote address about the pain care act. Rep. Rogers was to become a valuable ally in the cause, and in 2006, ACPA and the other PUP members visited him in Washington and held a press conference on the steps of the Congressional Office Building.

To help our partners connect with their legislators on this issue, we developed tool kits of documents for visiting local representative offices and for requesting a proclamation from a state governor to declare September as pain awareness month.

In 2003 and 2004, ACPA also created tools kits to help nurses and pharmacists aid people with pain.

September 12, 2006 was the first Global Day Against Pain in Older Adults, sponsored by the International Association for the Study of Pain (IASP). ACPA developed a tool kit for health care providers in September 2007 that addressed pain in older adults.

In 2008, the National Pain Care Policy Act of 2007 passed the House of Representatives. It is now under review in the Senate, as an amendment in the 2009 national health care reform bill.

The National Pain Care Act addresses the barriers that people with pain encounter when trying to obtain a proper assessment, diagnosis, treatment and management of their pain. (Read more about the Pain Care Act in the ACPA *Chronicle*, Fall 2007.)

In May 2009 ACPA undertook advocacy training with ACPA facilitators, enabling them to do pain awareness activities this September. Around the country, people with pain and members of the pain community will:

- Ask for a proclamation from their Governor to declare September as Pain Awareness Month in their state
- Give presentations on pain management to community groups
- Write letters about REMS before the June 30 deadline
- Participate in health fairs with a booth about ACPA and their own support group
- Get involved in community service projects to show that people with pain have abilities—no matter how limited—and can contribute to the community.

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Board Member Profile: Joanne Schneider

This is part of a series of articles intended to give readers more insight into the interests and contributions of ACPA board members.

Board member Joanne Schneider, MSN, CNS, CNP has helped many people with pain travel the journey from patient to person. She is a psychiatric clinical nurse specialist and adult nurse practitioner in psychiatry/pain medicine in the Neurological Institute Center for Pain at the Cleveland Clinic.

Joanne joined the board of the ACPA four years ago. She became acquainted with Penney Cowan when Penney first met with Ed Covington, Director of the Neurological Center for Pain in the Neurological Institute. That meeting was the spark that led to the formation of the American Chronic Pain Association.

Joanne has worked as a multidisciplinary team member in the Chronic Pain Rehabilitation Program in Cleveland for 23 years, treating individuals with chronic pain, addiction, and psychological issues. "I fully support the mission of ACPA, and the idea of helping patients move from patient to person. It is so important to have a good quality of life despite the pain," she said.

As part of her role at the clinic, she evaluates patients to assess their pain and plan their treatment. She is keenly aware of the need for follow up to review outcomes, medication management, and psychotherapy.

"People need to reduce the physical and emotional toll that chronic pain imposes and live a life that goes beyond the pain," she said. "There aren't that many pain rehabilitation programs nationwide, but people from all over the country are helped by the ACPA, people with all kinds of conditions and ranges of pain."

When she started on the board she served as secretary. She promotes the messages of ACPA in her work educating nursing staff, medical students, and medical residents in the art of pain management. "When I talk to patients and groups, I always bring up the ACPA as a resource, use our handouts, and reference the Web site," she said.

"Penney has done a tremendous job in helping the organization grow throughout the U.S., and now through the Internet, around the world. That's phenomenal," Joanne continued. "We need to build the program and help support groups use the manual to help people with pain continue their journey."

Joanne described ACPA as an invaluable resource for people with pain, particularly in directing them to reputable sources of information online. She said, "I always tell my patients to watch where you do your research on the Web and that the ACPA can be trusted."

Tribute

In Recognition of
Sally Price
Lynchburg College
Class of 1966

Welcome to these new support groups and facilitators.

Jennifer Starbuck
Lodi, CA

Felesha Williams
Rockmart, GA

Alisha Kujawa
Humble, TX

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A Letter to the ACPA

If I didn't know better I would say that there is a concerted effort to rebuild the governmental and medical barriers to effective pain relief that the pain community has sought to break down over the past decade.

The FDA has proposed restricting long-acting, extended-release opioids as part of its Risk Evaluation and Mitigation Strategy (REMS). Now we learn that the FDA is considering a ban on Percocet and Vicodin, two of the most depended upon short-acting pain medications. Both of these medications contain acetaminophen (Tylenol), which can cause liver damage when patients exceed recommended dosages or when they combine them with alcohol.

I don't believe that a ban should be placed on either of these medications. Instead, I believe that all care providers who have prescribing privileges and all nurses who have direct patient contact should complete continuing education specifically on pain management.

This continuing education should be mandatory and include short-acting opioids (including Vicodin and Percocet) and all long-acting opioids, covering new pain medications that were not available 10 or 20 years ago.

As a person living with chronic pain, I have received very little education on my medications. I learn nothing about

- Side effects, beyond constipation
- How to store my medications
- The dangers of alcohol
- What can happen if I take too much

They never point out how many over-the-counter medications have acetaminophen in them and that a dose of these OTC preparations, along with my prescribed medication, would put me over the dose that is considered safe. I have also never heard a commercial for Tylenol specifically state its potential for liver damage.

Like all opioids, Vicodin and Percocet come with an educational insert, which is rarely read. Because these medications are of the weaker class of opioid (intended for moderate pain rated as a 4, 5 or 6 using the 0 to 10 pain scale) people with severe pain end up taking more medication than is safe in an attempt to obtain adequate relief.

Studies show that nurses and physicians underestimate severe pain; some do not "feel comfortable" prescribing any of the stronger opioids, leaving patients with undertreated and uncontrolled severe pain.

People whose pain is not being managed properly will sometimes do drastic and unhealthy things to get relief, like take unsafe doses of weaker medications, in an attempt to get their pain back under control.

Margo McCaffery, a leading pain management nurse, says that "Pain is whatever the experiencing person says it is, occurring whenever he says it does." A ban on these medications will only cause patients and healthcare providers to turn to other medications such as ibuprofen (Moltrin) and hydrocodone.

Those of us living with chronic pain who are taking over-the-counter medications, or are on long-term opioid therapy, need to educate ourselves.

- We need to communicate our pain levels to our healthcare providers and update them as necessary.
- We need to have realistic expectations about opioids that reduce pain, not take it all away.
- We need to take responsibility for what we put into our bodies.

Avoiding an acetaminophen overdose requires that we read over-the-counter medicine bottles. Each extra-strength pill contains 500 mg and each regular-strength pill contains 325 mg. For the average healthy adult, the recommended dose over a 24 hour period is 4 grams (4000 mg) or eight extra-strength pills. A person who drinks more than two alcoholic beverages a day, however, should not take more than 2000 mg over a 24-hour period as they are more prone to developing acetaminophen-induced liver damage.

If you are having a flare up that pain medication and self-care methods are not adequately relieving, call the doctor. Do not take more medication than instructed and then call the doctor when you have run out of your prescription. By then not only have you damaged your relationship with your doctor, but also perhaps also damaged your liver.

The increased attention, advocacy, and funding over the last decade has lead to greater scientific understanding of pain mechanisms and pain treatment. Over the past decade opioid therapy has significantly increased due to the growing recognition and acceptance among physicians.

A significant source of pain relief has finally been made available to thousands of people living with chronic pain who need these life preserving, life saving medications. Though by no means are opioid medications a panacea, they have rightly become the standard of care in the modern treatment of intractable pain as they are the most effective form of treatment available. Let us not go backwards by creating more barriers to effective pain relief and decreasing the options available to legitimate pain patients.

Banning these medications is not the answer, better education is.

Jana Hamik
Facilitator of the Sebastopol, California ACPA Support Group

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