



CHRONICLE



Thirty Years of Wellness

by Penney Cowan, Executive Director, ACPA

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For six years, I looked for answers that would release me from a life that had become filled by pain.

When I finally heard that someone could help me, I did not believe that it was possible. I had tried everything to no avail. How could learning to live with my pain be possible? If it were that easy, I would have figured it out by now. Therefore, when offered the opportunity to learn to live with my pain, my first thought was, "That is impossible."

However, my husband felt strongly that this was the answer we had been looking for the past six years. I was convinced otherwise and thought, "This will not work and I'll go just to show you that it won't." So, I entered a pain management program as a patient at the Cleveland Clinic under the direction of Dr. Edward Covington on October 31, 1979, with every intention of failing.

Six weeks later, on December 14, 1979, I left the pain management program as a person. It was a long and difficult journey, but I had regained control of my life, increased my level of functioning 20-fold and improved the quality of my life 100 times over.

On the drive home, many thoughts were going through my mind. For the first time I saw that I was not the only person with pain. There were many others who were also living with pain. That was such a validation for me. I was not alone!



What I had learned on the pain program allowed me to move from a dysfunctional person (holding a cup of coffee was difficult for me) to that of a functional person. The skills they had taught me were too good to keep to myself. I knew there were others who could benefit from what I had learned. Knowing they were not alone would be such a powerful message for them.

Wanting to share my newly found skills and help others through support groups was one reason I started the American Chronic Pain Association. However, my most compelling reason for starting the ACPA was that I was afraid. I was afraid that what I had experienced on the pain program, while very effective, might not last once I was home and back into my "normal" routine.

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The Magic of Peer Support

by Erin Kelly

Jean Bascombe's work in peer support started when she struck up a conversation with a neighbor's niece. The woman was 20 years younger than Bascombe, but both were struggling with chronic pain and they found common ground right away. "We started talking, and each of us said that we felt so alone," Bascombe explains. That experience led Bascombe to start a peer support group named NFAA: Never Feel Alone Again.

This story points out one of the most important things a peer support group can do: reduce feelings of isolation. But peer support can do much more, both for the group members and for the organizers who create and lead groups. The companionship, understanding, role models, and ideas that peer support generates are a vital part on the ongoing journey from patient to person.

People Who "Get It"

Living with chronic pain is an unusual experience, but not a unique one. Whether you are dealing with serious problems like feelings of worthlessness or trivial concerns like an annoying heating pad, talking to people who've "been there" can help. "So many people who come to the group for the first time thought they were alone in having these problems," Bascombe says, "but they're not."

Jerry Becker, an ACPA facilitator in the New York City area, compares his peer group to "a warrior clan." Becker lists several reasons why it's easier to communicate with others who have chronic pain.

"They believe you when you describe your level of pain, they understand that you're not exaggerating, and accept that you're not a hypochondriac," he says.



A strong peer support group can be like a surrogate family.

Becker says peers are familiar with the negative emotions you're going through and they understand that if you take opiate pain medications you're not doing it for fun. People without pain can have a hard time understanding these things, so it can be easier to talk to peers in a support group than to family members or close friends.

Theresa Hesse, an ACPA facilitator near Dallas, Texas, says that peer groups are especially useful when it comes to understanding family dynamics. "There are a lot of relationship changes in a family when one member has chronic pain," Hesse says. "Peers understand that there's a lot of sadness and guilt involved if you can't do things you want to do, like go to a child's baseball game."

Family members without pain can find it difficult to sympathize with your mental state when they feel hurt by your actions. Group members know that acknowledging the emotional pain

is a step toward moving through it and will help you focus on what you can do instead. "I try to remind them that if they miss one event, they'll probably make the next one," says Hesse.

Peer support can come in different forms. Group meetings are very useful, especially for people in the early years of learning to live with chronic pain. But many people also help each other over the phone and by e-mail.

Becker, a 20-year veteran of living with pain, retired from leading a bimonthly support group after more than 10 years. He still works as an ACPA facilitator by providing resources by phone and over the Internet. He also has close friends that make up a long-distance support group for him. "I always have somebody I can call up when I need to talk," he says. "You have to have people you can count on. You need somebody to vent to."

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It can be easier to talk to peers in a support group than to friends.

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Personal Stories and Personal Touches

Peer groups offer a different kind of help than you get from professional counseling. “I don’t have boundaries like professional therapists have to keep them from getting too close,” Hesse explains of her role as a facilitator. “I have a very open personality and I’m a big hugger.” By sharing personal stories and feelings, she encourages others in the group to open up about their concerns.

Bascombe says her group, based in eastern Pennsylvania, benefits from a feeling of openness and intimacy. “It’s like a little family,” she says. “We all trust each other and share with each other.” She says this level of sharing wouldn’t be possible without trust. “Confidentiality is one of the most important things in the group,” she says. “There’s a sense of honesty—everyone is able to say what they want to say. In a group you can vent your frustrations more easily than you can with friends or the people you meet in your doctor’s office.”



In bad times, a strong peer support group can be like a surrogate family. “Everyone in the group is an important member of the team and we make sure they know it,” says Becker. “We care about you, we love you, and we need you—even if it seems like your relatives don’t.”

Groups also can be a social outlet. Bascombe says her weekly group has started meeting for lunch at a restaurant once a month instead of their regular evening meeting. Becker’s group scheduled holiday parties and outings for dinner and theatre in addition to their regular bimonthly meetings in a church meeting room.

Role Models Who’ve Been There

Group facilitators also can provide an example of how to live with chronic pain. Becker recovered from “rock bottom” with the help of a multidisciplinary pain management program in the mid-1980s and was able to return to teaching full time. He got married and maintained a low pain level for years mainly by controlling his weight and using exercise and biofeedback techniques. “I was lucky that I was able to take the program’s teaching to heart,” Becker says. He realizes that the four-week intensive inpatient program he participated in is a luxury that few people have access to these days and he wants to pass on what he learned there.

“I have \$100 million worth of knowledge to give away for free,” he says. He tries to help people understand that their pain won’t be “cured,” but that they can improve how they feel by taking responsibility for their own health through exercise and lifestyle changes. “I’m doing well, but that’s because I work out 45 minutes every day. I meditate every day for 15

minutes, and my diet is the way the FDA says it ought to be, with meat at the top of the pyramid and fruits and vegetables at the bottom,” Becker says. “It’s not easy and it’s a long journey.”

Hesse meets with people in a pain management program and they often comment that she “doesn’t look hurt.” In her 18th year of living with chronic pain, Hesse has learned to manage her symptoms and her mindset, so she doesn’t carry herself like a person who is hurting—at least, not most of the time.

“I drive an hour each way to get to group, although 30 minutes in the car is usually my limit,” she says. “When I walk into the building I’m not always in the best shape.” She uses ice packs, rest, and relaxation techniques to recover from the drive before starting the meeting. But Hesse believes that how she handles a flare-up can be educational for the others in the group. “I think it helps that they sometimes see me in a little bit of trouble,” she says. “When I have that kind of pain, it’s just physical, and I can manage it.”

As a mother with chronic pain, Hesse also uses her experience to reassure parents that they can still do a good job at parenting by thoughtfully choosing how to spend their energy. “I see mothers with pain who don’t know how they’ll be able to take care of their children,” she says. “I tell them what I’ve learned: If the kids are fed and healthy, it doesn’t matter if the laundry isn’t done or the house isn’t clean. My kids need me—my personal attention and affection—more than they need clean laundry.”

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The Magic of Peer Support

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Bascombe feels as if she is a role model for her group members, but also that she sometimes serves an example of what can happen when things go wrong. Her support group includes people with chronic pain, neuropathy, and diabetes—a disease that's taken a toll on Bascombe herself. "I've lost sight in one eye and had a toe amputated because of diabetes," Bascombe says. "I want to prevent others from going through that." Despite her outcome, sharing her story with her peer group has been rewarding. "People tell me they work hard to control their diabetes because they don't want to become like me," she says.

Helping Yourself By Helping Others

In a peer support group, members get help and give it at the same time. "I've always been a caregiver," says Hesse, "and it took me a long time to find some way to be a caregiver in my life with pain," she says. "There's such a tremendous feeling when you know you've helped even one person."

For people who struggle to feel useful after having to give up work or house-

hold tasks, helping others is one way to boost feelings of self-worth. "It gives me an enormous amount of joy to be able to help other people who are in the position I was in," she says.

But it's not always easy. People with pain can be angry and rude and reluctant to participate. "Pain can change people's personalities, like Dr. Jekyll turning into Mr. Hyde," says Becker.

Bascombe says she sometimes meets people who are so consumed by pain that "they're not even able to talk to you in a nice way." Because she remembers when she felt that way, she can be patient when trying to help those people. "I used to be that miserable person," Bascombe says. "I've come a long way."

When she is able to help someone turn his or her life around, the reward is worth the emotional and physical effort. "Last December I wasn't doing well at all, and my doctor asked me, 'Are you sure your work with the group isn't pulling you down?' I said, 'Absolutely not. Trust me, it helps me,'" Bascombe explains.

The kind of help peer groups provide goes beyond emotional support. Group members often share practical tips for reducing pain or just making life go more smoothly. Talking to other people can give you a new perspective and new ideas for how to handle problems big or small. "Our members might not have the same diagnoses, but we are able to listen to each other and provide useful feedback," says Bascombe. "We come up with a lot of spontaneous tips and suggestions. Even people who've had diabetes for 10 years have learned new things in our group."

One week Bascombe arranged for a member of her group to give a talk on the various remedies he'd tried for diabetic neuropathy. "Obviously, we can't recommend any medications, but he talked about the different creams he'd tried and what he thought of them," she says. "He gave other ideas too, like to fill soda cans with water and freeze them, then roll your feet on them when you have foot pain." Not only was it useful information, it was an opportunity for the member to use his professional skills. "He was an excellent speaker," Bascombe says. "If I ever make it on Oprah to talk about chronic pain, I want him to come along!"

Your doctors, therapists, family, and friends are all important for helping you live well with chronic pain, but none of them can replace the kind of help a peer support group can give. Sharing your experience with others like yourself can teach you new ways to handle your challenges, provide a supportive outlet for frustrations, and even give you the satisfaction of making a difference in another person's life.

Improve Your Communication Skills

by Alison Conte and Erin Kelly

In managing chronic pain, it is important to express your wants, needs, hopes, and problems to your health care providers, friends, and family. But this requires good communication skills, both for talking and listening. To communicate well you must:

Identify Your Needs: Tell others exactly what you need; never assume that others should be able to read your mind. Though it is nice to get help with the dishes without asking, don't blame others if they don't respond. You haven't asked!

Repeat What You Heard: When talking with family members or physicians, tell them, "This is what I heard you say. Correct me if I misunderstood." Then repeat what you think they said so there will be no confusion.

Use Feeling Words: Sharing your feelings is helpful when trying to describe your reaction to others' words or actions. Try saying "I feel angry when this happens" or "I feel happier when you say that." Try not to blame others for your feelings. Take responsibility for what you do and feel.

Verify the Emotions of the Listener: Share your interpretation of how you think the listener feels. "You seem bored with me. Are you tired of hearing about this?" Then they can confirm how they feel without worrying that they are hurting you or by making you guess. Some ACPA facilitators offer these specific suggestions for people with chronic pain who want to improve communications with medical professionals, friends, strangers, and family.

- * **A printed note can help explain to new acquaintances why you'd rather not shake hands, be touched on the shoulder, or hugged.** Deborah Daly, who leads support groups in San Diego, California, suggested something short and sweet like: "I appreciate touch, but sometimes it might hurt me. It's nothing personal and I don't mean to be rude."
- * **Sometimes it's easier for family members to accept information from a doctor or medical resource.** Catherine Cartwright, an ACPA facilitator from Vallejo, California, said, "It's better if they can hear from the medical provider directly." Daly and her family use the Internet to circulate articles about her medical conditions. "My daughter keeps a mini library of the resources we've found for everyone in the family to use," Daly said.

* **Accept and validate the experiences of others.** "In a support group or in a family, you should never deny or doubt another person's experience or opinion," said Cartwright. Every person is unique, and every situation is different. Worrying about whether someone's reaction is "right" or "wrong" is unproductive.

* **Find common ground when trying to explain your situation.** Daly compares her pain to the pain you feel when a dentist hits a nerve in your tooth, or when you hit your "funny bone"—only stronger and lasting much longer. "Those are things that almost anyone can relate to," she explained.

Just as people with pain appreciate talking to others—perhaps in a support group—who have lived with similar situations, a caregiver support group can provide an outlet for spouses and children. There, they can talk to people who truly understand their unique frustrations.

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Solutions for Sleepless Nights

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

A good night's sleep is an important component in maintaining health and pain control. But about 30 to 50 percent of the general population is affected by insomnia and 10 percent have chronic insomnia, according to WebMD (www.webmd.com). Why should something as simple as "sleeping like a baby" be so hard to achieve?

Insomnia is described as difficulty falling asleep or maintaining sleep throughout the night. Although there are many types of insomnia, this article will focus on the causes of chronic insomnia and offer suggestions on improving the quality of sleep.

Individuals with chronic health conditions are at a higher risk of insomnia, due to the medications they are taking, their bodies' physiological reactions to chronic pain, and any anxiety and stress caused by their medical diagnoses. Individuals who are sleep deprived may experience drowsiness, difficulty concentrating and remembering details, and irritability. To avoid these adverse effects, it may help to learn about the activities, medications, beverages, and foods that can interfere with sleep, so you can modify your behavior and achieve better sleep patterns. Here are 10 tips to avoid sleep problems:

1. Reduce the level of stimulation before bedtime.

Start by decreasing the noise level in your bedroom and any room you are in during the evening. Whether you are watching television or listening to music, start to lower the volume slightly and dim the lights at least one hour before retiring. This may help decrease the amount of stimulation your senses and body are exposed to. It is also a good idea to avoid using a computer in your bedroom.

2. Establish a regular bedtime routine and adjust bedroom temperature.

Go to bed and get up in the morning at the same time each day, even on the weekends. In addition, if a bedroom is too hot or too cold, it may affect your ability to get to sleep. For some peri-menopausal and menopausal woman, a good night's sleep is dependent on adjusting the thermostat or number of blankets to achieve different temperatures throughout the night.

3. Avoid foods and beverages that negatively affect sleep.

- * Any food that is spicy, hot, or has the potential to cause gastrointestinal upset should be avoided at dinner time.
- * Avoid beverages with caffeine, such as tea, coffee, cola and other soda pop, or chocolate at least eight hours prior to bedtime.
- * Contrary to what you might think, alcohol can interfere with sleep. While you may drop off quickly, you can wake up in the middle of the night dehydrated and restless. Stop drinking alcohol at least two hours prior to bedtime.
- * The body works hard to metabolize protein foods like meat and cheese. This can interfere with the body's ability to relax and induce sleep.
- * Limit the amount of fluids you drink before retiring. If you have an overactive bladder, you may want to limit fluids two to three hours prior to bedtime.
- * A light evening snack that contains tryptophan may assist in relaxation and falling asleep. Tryptophan is in cheese, eggs, cottage cheese, milk, nuts, brown rice, bananas, and turkey.

4. Avoid medications that interfere with sleep.

Check with your pharmacist to see if the prescription or non-prescription medications you take could be affecting your sleep. If you suffer from chronic pain, check with your physician to make sure that your pain medication is adequate throughout the night so pain is not contributing to your insomnia.

Some non-prescription medications contain caffeine, which can interfere with sleep. These include Darvon Compound, Fiorinal, Excedrin, and Midol. For a more extensive list go to <http://wellness.uwsp.edu/medinfo/handouts/LAs/Caffeine.pdf>. Some drug categories that negatively affect sleep quality are corticosteroids, diuretics, antidepressants, beta blockers, nicotine, and alcohol.

5. Develop an effective exercise program.

Although a routine exercise program may reduce or help prevent insomnia, don't engage in aerobic activity later than three hours before bedtime. Some individuals feel that gentle stretching exercises prior to bedtime help their bodies to relax.

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6. Take a bath.

Many people find a bath relaxing prior to bedtime. However some women find that a very hot bath can trigger hot flashes, which can interfere with sleep. So plan your bath time accordingly.

7. Learn to relax.

Educate yourself about various relaxation techniques and try progressive relaxation, meditation, or imagery one to two hours prior to bedtime. Remember to use your bedroom only for sleep, relaxation, and sex. All work or study activities should be done elsewhere.

8. Happy thoughts only; do not concentrate on mental or emotional problems.

Your thoughts and images prior to bedtime will also affect your sleep. Along with trying relaxation techniques, try to establish a habit of not focusing on or ruminating about problematic or painful emotional issues at least one hour prior to bedtime.

9. Bed and pillows should be comfortable.

Check your mattress, box spring, and pillows to make sure they are not worn out or have lost their supportive qualities. You may want to flip your mattress every few months. If you have developed any new neck, back, or hip pain over the past few months you may need a new bed.

10. Keep a sleep diary.

A sleep diary can be very helpful in working with your physician or nurse consultant on your sleep problems and overall health. (You can add your sleep habits to your [ACPA Pain Log](#) for a complete review of your condition.) Bring it to your appointments for the health professionals to review. With a sleep diary, you keep a record—for one to four weeks—of your daytime and evening activities, revealing activities that are thwarting your ability to sleep well. Note the time of day for each activity.

For each day, list the time you went to bed, how long it took to fall asleep, how many times you woke up during the night and behavior that occurred as a result of waking up, total hours of sleep, quality of sleep, and any other pertinent data. Include your general mood and stress levels, during the day

and night, as well as thoughts which awaken you in the middle of the night. Using the [ACPA Pain Log](#) will make it easy to track these factors, as well as your activities.

You should also provide the time of day that you ingest:

- * Vitamins, non-prescription, and prescription medications
- * Foods (including snacks) and beverages (including alcohol)
- * Caffeine or nicotine

If your sleep habits do not improve after trying these suggestions, ask your physician about a referral to a sleep clinic or sleep specialist. For assistance in getting your insurance to pay for this treatment, read *Navigating Through the Insurance Maze* in the [March 2009 ACPA Chronicle](#).

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REMS: Fighting Drug Abuse or Limiting Access? How Risk Evaluation and Mitigation Strategies Could Affect You

By Kathryn Keller, PharmD, CPE

The Risk Evaluation and Mitigation Strategy (REMS) requirement was created by the Food and Drug Administration (FDA) with great intentions. In recent decades, the agency observed a perceived trend of increasing adverse drug events associated with the abuse and misuse of prescription opioids. So they conceived of a program called REMS as a way to reduce the chance that these drugs would get into the hands of people who have the disease of addiction. This was an attempt to protect them from the harmful effects of misuse.

This alarming trend is documented in various studies. Despite the many restrictions and cautions already on these controlled drugs, the 2002 Drug Abuse Warning Network (DAWN) data showed there were 108,320 emergency department visits for treatment of events due to opioid analgesics, which is a 153 percent increase from 1995 statistics.

- * Opioid analgesic misuse issues can include such events as “pharm parties” with inadvertent deaths (particularly in youth), physician-prescribing errors (as has been seen with methadone, for example), inappropriate patient selection when prescribing rapidly-acting opioid pain relievers like Fentora™, as well as persons simply failing to heed their physicians’ advice on how to take and store these drugs correctly.
- * Teenagers report it is often easier to get prescription drugs than beer, according to a 2008 National Center on Addiction and Substance Abuse survey.
- * Drug treatment admissions for non-heroin opioids as primary drug rose 350 percent from 1996 to 2006.
- * The 2007 National Survey on Drug Use and Health (NSDUH) states that 33.5 million Americans reported they used a pain reliever “non-medically” at least once in their lifetimes (a 13 percent increase from 2002).

Recently, news sources reported that trucks delivering medications from pharmaceutical manufacturers to distribution centers were hijacked by sophisticated pirates. Not only were some drugs diverted to non-prescribed users, but other medications were left unrefrigerated for a dangerous time period, making them unsafe for use by legitimate patients.

Starting REMS

Congress responded to these alarming trends by asking the Institute of Medicine (IOM) to evaluate the U.S. drug safety system. In 2006, the IOM responded with “The Future of Drug Safety: Promoting and Protecting the Health of the Public.” It says that the FDA must “balance expeditious access to drugs with concerns for safety” and focus on three areas:

- * Strengthen the science for safety surveillance at every stage
- * Improve communication flow to all stakeholders
- * Improve operations using some of the Prescription Drug User Fee Act (PDUFA) funds to enhance implementation of review, analysis, and communication processes.

REMS is a system initiated by the FDA under the authority of the Food and Drug Administration Amendments Act (FDAAA) of 2007 to assure that the benefits of drugs outweigh their risks. It expands FDA’s monitoring and regulatory authority from the pre-approval stage to include gathering post-marketing information from various sources. Also, FDA now has the authority to alter approval status or conditions in the post-marketing period.

The next step happened in March 2008, when the FDA identified 28 drugs or biologicals, both brand and generic, that would be required to have specific REMS requirements. Since then, the list of REMS drugs has grown much longer. It can be reviewed on the [FDA Web site](#).

In February 2009, the FDA told 16 manufacturers of long-acting (LA) opioids to submit proposed REMS for their drugs. The FDA directed the companies to work cooperatively to achieve consistent safe practices. The discussion about LA opioids continued with a stakeholders meeting and public meeting with the FDA in May 2009, and, in December 2009, the first Industry Working Group public meeting.

What Does a REMS Include?

FDA’s draft guidance says REMS must include these elements:

- * Medication guide/patient package insert
- * Communication plan for healthcare providers
- * Elements to assure safe use
- * Timetable, recommended format, and FDA contacts

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Developed to protect people from the harmful effects of misuse



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As an example, one of the current opioid REMS is for Onsolis™ (fentanyl buccal film) and is termed the FOCUS™ program. It has a medication guide, communication plan, elements to assure safe use, and an implementation system. It states that prescribers and pharmacies must be tested and registered and that people needing the medications must be identified and enrolled in the program. The prescription is delivered by courier to the approved pharmacy, then couriered to the patient's home. The FDA is planning similar programs for Actiq™ and Fentora™.

The REMS for Embeda™, which contains morphine sulfate and naltrexone hydrochloride, is considered 'interim' and includes a medication guide and communication plan.

How Will REMS Affect You?

You should consider that putting security in place to comply with the REMS will be expensive for manufacturers, and possibly for pharmacies, physicians, and people with chronic pain who need these medications to function in daily life. If only certain physicians and pharmacies are "registered" to receive these drugs, access will become more difficult for some people, particularly those in rural areas.

Privacy issues are part of the discussion, as doctors and people with pain consider being identified as drug users. Obtaining your medications will become more complicated, with restrictions on the transmission of prescriptions and delivery of some analgesics only to your home and not to the drug store.

Is all this security, education, and precaution necessary and sufficient? One case study points out the need for stricter controls and clearer instructions. A letter to the editor by Dr. David H. Jang entitled, "Severe Opioid Withdrawal Due to Misuse of New Combined Morphine and Naltrexone Product (Embeda)" recently appeared in the *Annals of Emergency Medicine*. (55 (1):303, March 2010.)

It reviews the situation of a 39 year-old woman with chronic pain who was taking 160 mg methadone daily. She received a prescription for Embeda (30 mg morphine/1.2 mg naltrexone). The article states: "For unclear reasons, she chewed her first dose prior to swallowing. It is not entirely clear if the

patient received proper instructions on how to administer her medication." She began to experience severe opioid withdrawal syndrome in 10-20 minutes and was admitted to a hospital intensive care unit for 24 hours of care.

The article goes on to say, "It is not clear whether this case represents a failure to counsel or an intent to abuse. Despite the use of an education-oriented REMS, this patient was apparently unaware of the risk of precipitating abrupt, severe, and recalcitrant opioid withdrawal by chewing the capsule."

While this example illustrates the level of danger in misusing medications, the added expense, complexity, and delays involved in enacting REMS protocols might change the pharmaceutical landscape. It could mean that drugs may be prescribed less often, that drug production would be halted, or even that fewer new drugs would be developed.

Imagine what this might mean for people who need these drugs to manage their conditions or illnesses, to function in a fulfilling life, or to continue living at all. The FDA assumes that we will adjust to the new regulations but we must also consider how many lives will be diminished or lost along the way.

More information can be found at the [FDA central Web site](#) for opioid drugs and REMS.

The FDA is accepting further public comments on REMS until October 2010. Further information on how to submit your opinions can be found in the [Federal Register notice](#).

Kathryn Keller has been a California licensed pharmacist since 1979. As a member of the American Society of Pain Educators (ASPE), Dr. Keller was among the first to become a Certified Pain Educator (CPE) in 2009. Her work was vital to the reinvigoration of the Northern California Pain Initiative (NCPI) and she has continuously served on the Advisory Council. Dr. Keller is currently an independent consultant pharmacist and joined the ACPA Board of Directors in March 2010.

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Interdisciplinary Pain Programs Focus on the Total Person

While medical science has made remarkable advances to eradicate some diseases, cure others, and extend life, chronic pain is still one area that doctors are struggling to understand. The good news is that they have made advances in helping people like you to manage your pain through [Interdisciplinary Pain Programs](#). These programs are designed to help you become part of the treatment team and take an active role in regaining control of your life in spite of the pain. The programs are focused on the total person, not just the pain.

What is Interdisciplinary Pain Management?

Interdisciplinary pain management is designed to offer a complete program from assessment, treatment, communication, and education through to follow up. The treatment is never focused on just the pain, but takes a holistic approach; who you are and how you feel is as much a part of shaping your treatment as your physical condition.

The interdisciplinary aspect means that your health care team is made up of many players:

- * "Patient" (the person with pain)
- * Significant others (family, friends, neighbors)
- * Physicians
- * Nurse practitioners
- * Physician assistants
- * Nurses
- * Psychologists
- * Physical therapists
- * Occupational therapists
- * Recreational therapists
- * Vocational counselors
- * Pharmacists
- * Nutritionists/dieticians
- * Social workers
- * Support staff
- * Volunteers
- * Others

Team members may vary from one program to the next, but the underlying goal remains the same: to help you live a full life. You might have noticed that the "patient" is at the top of the list. Without your willingness to travel from patient to person by taking an active role in the program, nothing that the program has to offer will be helpful since there is currently no cure. Your efforts are the key to success!

Benefits of a Well-Functioning Team

In an interdisciplinary pain program, a team of professionals meets on a regular basis to review your care and discuss it with you. They will look at the goals that have been set, what you have accomplished, and where you are having difficulties. Based on that they will evaluate what the next best steps are for YOU.

Assessment

When you are being considered for an interdisciplinary pain program you will see various staff members who will evaluate different areas of your health and ability. This is where the treatment goals and expected outcomes will be identified.

Treatment

Each professional will be part of the treatment plan, working together toward your treatment goals. This, of course, means that you, too, must be an active participant in your treatment. The goals should be clearly stated, focused, realistic, and measurable. There will be an on-going assessment of progress.

Communication

Lines of communication must remain open for everyone involved. In addition to the treatment team, your primary provider, insurance company, and your family should be involved at some level. Although there are common goals for the entire team, each team member may focus on specific issues toward your goals: improved quality of life, reduced sense of suffering, and increased level of functioning, both physically and emotionally.

For example, a physical therapist may be focusing on upper body strength, flexibility, and endurance with the general goal to improve physical function. A psychologist may focus on increasing communication skills, recognizing emotions, and increasing self-esteem with the goal of improving your overall outlook. A nurse may address components of a healthy lifestyle, while a physician may attempt to find the medications that work best for you.



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Communication among the team members on a regular basis is a critical part of the overall effectiveness of the efforts.

Education

Fear of the unknown can be a controlling factor. For a person with pain, entering a pain program can be overwhelming. This is eased if a “blueprint” of the program from beginning to end is clearly defined at the onset. Then you know what is expected of you and what you can hope for after the program is completed.

Afterwards, Some Pain May Remain

When you are an active part of the program you are watched and evaluated closely to track your progress and identify problem areas. However, when you leave a program that is no longer the case.

Even when a program is successful, you may still have some level of pain, still need medications, and in some cases additional treatments once you complete the program. You will have to take responsibility for continuing any exercise program, practicing the pain management skills you learned, and communicating appropriately with family members and health care providers. Pain programs do not take away your pain or take you back in time to before the pain began. Life can be improved greatly by completing a pain program, but you may still have limitations and need to be seen on a regular basis by your primary care provider. The goal of the program is to improve the quality of your life, increase your level of functioning, and reduce your sense of suffering.

Outcomes of the Program

There has been increased evidence that an interdisciplinary pain management program can (in varying degrees):

- * Reduce dependence on health care
- * Increase ability to return to work
- * Improve quality of life
- * Increase function
- * Reduce pain levels
- * Lessen sense of suffering
- * Provide the skills to manage pain on a daily basis.

Hearing that you may have to live with pain sounds like an impossible task and it can be if you do not have the right direction, intervention, and skills to move from the mindset of a disabled patient to the attitude of a functional person. Living with pain is possible and having the opportunity to take an active part in an interdisciplinary pain program provides the best opportunity to accomplish that in a cost-effective and timely manner.

Finding and Evaluating an Interdisciplinary Pain Program

There are a number of practices and facilities that are called pain clinics. While they may address specific pain problems, they often do not offer the complete package needed to help a person regain control of his or her life.

It is important that a program provide you with the physical, emotional, and psychological components you need. Perhaps the most important step is to meet the team and make sure that you feel comfortable with them. If you are not comfortable with the team, it will be much more difficult to make progress. A well-functioning interdisciplinary pain team should:

- * Share the same beliefs and mission
- * Be patient and family centered
- * Work together for common, agreed-upon goals
- * Develop treatment plans based on individual needs
- * Have mutual respect and open communication
- * Frequently communicate between primary provider and team members
- * Monitor progress toward goal achievement
- * Understand that meeting the goals of each person in the program is an ongoing responsibility of all team members
- * Share feedback about progress and performance with participants, caregivers, significant others, and primary care providers
- * Schedule formal follow-up

Adapted from: Interdisciplinary Pain Management: Dennis Turk, et al. Task Force Report developed for American Pain Society. 2009; American Chronic Pain Association; Copyright 2009.

ACPA Updates



New Web Site Launched May 5, 2010

ACPA debuted a new Web site design in May, providing a better user experience with more features to help people with pain.

The Web site now has:

- * An enhanced video delivery system
- * Better navigation to help you find the specific topics you are searching for
- * An A to Z guide for specific medical conditions
- * A [glossary of healthcare terminology](#), with links to additional resources
- * An expanded section for pain management tools
- * Additional interactive content
- * A daily affirmation to inspire and heal the spirit

Find us in the same place—www.theacpa.org—and let us know what you think.

Join Us on Facebook

ACPA has started a group page on Facebook. We hope this will expand our reach to new audiences. We will also post notices of events, upcoming legislative action, and links to programs, services, and support groups. We also have included a few videos and relaxation exercises. To become a fan or just see what's new, follow the link on our [Web site's news page](#).

Past and Future Gatherings

The ACPA board met in California on March 5 to 7. Topics included the use of new media to reach more people with pain and their supporters, current pain issues and challenges on which the ACPA can take action, and strategic planning for the future of the organization.

From May 21 to 23, the ACPA held a media and advocacy training session in Pittsburgh for more than two dozen group facilitators and regional directors. The goal of the session was to prepare people with pain to be more articulate spokespeople for themselves and others with pain. We also worked to energize these leaders to create local and regional activities to call attention to the issues of living with pain during September's Pain Awareness Month.

In October the board will host a 30th anniversary celebration and honor past board members who have contributed to ACPA over its three decades of service. Watch for the September issue of *The Chronicle*, which will highlight the history of the ACPA.

Thirty Years of Wellness

CONTINUED FROM PAGE 1...

In the past, I had experienced a few successes in treatment that reduced my pain levels. I still remember how excited I was to think that the pain nightmare was ending, only to find out that the relief was short-lived. It was my fear of the pain returning that motivated me more than anything to begin a support group for people with pain.

I knew that if I was to stay in the role of a person actively involved in pain management—not a passive patient—I would have to continue with all the skills I learned while on the pain unit. What better way to receive reinforcement than to share knowledge with others! That revelation was realized in 1980 when the first American Chronic Pain Association group met in Monroeville, Pennsylvania.

Of course the ACPA has grown significantly over the past 30 years. Today several hundred ACPA support groups meet across the U.S. and in many other countries. The ACPA has developed a wealth of tools to help people with pain live fuller, richer lives. And each day I learn something new about pain management, human courage, and determination.

In the 31 years since I left the pain management program at the Cleveland Clinic, I have remained a person. I am a testament to the truth that it really is possible to live a full life in spite of pain, but the key is for the person with pain to take an active role—and remain active.

In this issue, you can read about how our [support groups](#) have been essential to ACPA's efforts teach pain management. Our members and facilitators discuss how when they reach out to help others, they are also helping themselves.

On a personal note, I have to thank each person who has become involved in the American Chronic Pain Association at some level. I want to thank you for allowing the ACPA to reach out to you. It is my hope that life has become a little bit brighter for you and your family because of it. Thank you!

In September 2010, The Chronicle will commemorate the 30th anniversary of the ACPA with a historical retrospective. If you would like to contribute a personal recollection of how the ACPA has affected your life, or a note of encouragement to the organization and its members, please send it to The Chronicle Editor, c/o The ACPA, PO Box 850, Rocklin, CA 95677 or to ACPA@pacbell.net.

Thank You!

Welcome to our new groups and facilitators.

Claudia Welch
Harbor City, CA

Karen Cummings
Oakdale, CT

Ronald Farris
Waltham, MA

Sheila Griffin
Somerset County, NJ

Adam Hesney
New York, NY

Danita R. Grice
Delaware, Ohio

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

AMBASSADOR

Pfizer

EDUCATOR

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Medtronic, Inc.
Purdue

BUILDER

Abbott
Endo
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PriCara
Roche

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

Pfizer for Fibromyalgia education campaign

Medtronic Foundation for redesign of the Web page

Forest Laboratories for the Fibromyalgia Web-based interactive person

King for support of Consumer Guide

Medtronic for Understanding Medical Devices DVD Web Cast

The ACPA is a peer support organization: we help each other learn to live fully in spite of chronic pain. Your membership, donations, and purchase of materials keep the ACPA alive and reaching out to even more people with pain.

Tributes

IN MEMORY OF
JOYCE DOMINICH
Given by Wally Deschene

IN HONOR OF
DR. SARAH WHITMAN
Given by Esther Gilbert

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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Board Member Profile: Kathryn H. Keller

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

Kathryn Keller, PharmD, CPE, joined the ACPA Board of Directors in March 2010, contributing her expertise in pain management, pharmacology, and toxicology.

A resident of San Rafael, California, Dr. Keller has been a licensed pharmacist since 1979. Most recently, she has worked as a field-based medical affairs liaison in the pharmaceutical industry where, she said, “I have focused primarily on pain management and addiction issues.” She has provided hundreds of consultations, lectures, and workshops on analgesic pharmacology and pain management throughout her career.

She received her doctorate in pharmacy from the University of California at San Francisco (UCSF) School of Pharmacy where she also completed her clinical pharmacy residency.

During this time Dr. Keller fulfilled a multidisciplinary fellowship in applied gerontology, a program administered through the Medical Anthropology and Medical Sociology departments at UCSF and sponsored by the Administration on Aging. “It was there I became acutely aware of the issues that older people deal with on a daily basis,” she said. “I also learned more about the dangers of misusing medication, leading me to work in clinical toxicology for the next 20 years.”

Dr. Keller worked on the hotlines at the San Francisco Bay Area Regional Poison Control Center, providing emergency consultation on overdose and poison-

ing management. “We were helping people: guiding physicians, emergency departments, workplaces, parents, whoever had a poisoning emergency,” she recalled.

As a nationally certified specialist in poison information she actively contributed to the scientific discipline of clinical toxicology through publications and teaching. She maintains her membership in the American Academy of Clinical Toxicology.

From Toxicology to Pain Management

Her next career move was to enter the pharmaceutical industry. “I was familiar with how depression could affect people with pain. I had seen how physical and psychological problems can result in an overdose and a much worse state of illness, or more unfortunately, an unnecessary death,” she said. “So many political and psychological issues surround pain management.”

Keller noticed that pain management curricula was virtually non-existent in medical and health science schools, despite the devastating mental, physical, social, and financial impacts for those who suffer with chronic pain. At the time, she was working with Purdue Pharma LP as a medical science liaison, helping to provide accredited continuing education programs in pain management for nurses, nurse practitioners, physician assistants, medical social workers, and case managers.

It was then she met Penney Cowan, executive director of the ACPA. “Penney agreed to talk to my colleagues in the San Francisco Bay Area End of Life Network. She later became involved in the Northern California Pain Initiative,” she said. “Collaborating with Penney furthered my understanding of the

issues that she was close to. I learned there is so more to pain management than writing a prescription.”

Keller received a graduate certificate in pain management from the UCSF Graduate Division in 2007. “I was reminded that most people in pain want the legitimacy of a diagnosis. Knowing the probable cause improves the way you accommodate to your pain,” she said.

Supporting Pain Initiatives

Dr. Keller has held a volunteer faculty appointment as assistant, then as an associate clinical professor of pharmacy at UCSF since 1982. She has served as a member of the Human Research Committee, the FDA-mandated Institutional Review Board serving UCSF, San Francisco General, and the San Francisco Veterans Administration Hospitals.

Dr. Keller was vital to the reinvigoration of the Northern California Pain Initiative in 2003 and has continuously served on the Advisory Council. She was recognized as a State Pain Initiative Champion by the Alliance of State Pain Initiatives in October 2009.

As a member of the American Society of Pain Educators, Dr. Keller was among the first to become a Certified Pain Educator in 2009.

“Of all the organizations I’ve been involved with, I think the ACPA has the longest history and the most experience providing ready access to reliable information and much-needed support for people with pain. I’d recommend anyone struggling with pain to go to the ACPA for guidance,” she said.

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