Growing Well with Pain
by Penney Cowan, Executive Director, ACPA

One of our basic needs is to eat and drink. Usually, we go to the store and buy what we need to fix our meals without giving any thought to how that food got to the store. We do not realize the time, effort, hard labor, back-breaking work, and sacrifice it takes to provide the food we depend on. We have been remiss in thanking a population of unsung heroes—our farmers and ranchers.

In early 2007, I was invited to take part in a conference call for an organization I had never heard of: AgrAbility. I was not sure what it was about but my interest was piqued. Why would they ask the ACPA to be on a call about agriculture?

It did not take me long to realize that AgrAbility represented a large population of people who were trying their best to live with pain. This was a population of farmers and ranchers that—in the 29 years since I began the ACPA—I had never thought about. Furthermore, they were clearly underserved and in need of the type of resources that the ACPA offers.

We then considered the question of how to reach them. They were spread out across the country and had little, if any, time to be traveling to formal presentations. Despite their illness, injury, or pain, this group did not have the luxury of taking time off or doing less than was needed. They couldn’t turn to others to lend a hand. When these farmers reached the end of a long day of very physical work—more demanding than most of us have ever experienced—their pain levels would increase.

The ACPA felt a strong need to help the people who provide us with our food.

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About AgrAbility
The AgrAbility Project was created to assist people with disabilities (including chronic pain) employed in small and large agriculture operations. It provides practical education and assistance that promotes independence in agricultural production and rural living. Read more about AgrAbility and the people it helps throughout this issue of *The Chronicle*. 
The Mission of AgrAbility

When you run a farm or ranch, it isn’t easy to take a day off, no matter how you feel. As farmers and ranchers manage arthritis, back pain, or pain from injuries, they may not have the same quickness, strength, or range of motion as they did before their pain.

The AgrAbility Project was created to assist farmers, ranchers, farm workers, or family members with disabilities—including chronic pain.

There are no fees for AgrAbility services, although costs for any assistive technology or accommodations recommended by AgrAbility specialists are not covered. AgrAbility specialists can help those who need financial assistance find ways to pay for these devices.

State and regional AgrAbility projects work to with other consumer organizations, health care agencies and other government agencies, to provide services that accommodate disabilities and prevent secondary injuries, network, and share resources.

The goal is to help a farmer continue to farm successfully, a task that may involve modifying the agricultural operation, buildings, or equipment.

ACPA Provides Support

“Telling a person with pain to ‘live with it’ sounds like an impossible task. We try to provide them with the necessary skills to move from the mindset of a patient to that of a person by taking an active role in the recovery process. This is so important for the farming community,” said ACPA executive director Penney Cowan.

“Together with the AgrAbility specialists in each state, we sought to empower people with pain and discuss the skills needed to help improve their quality of life,” she said.

Tools to Help Farmers Work

Assistive devices developed for farmers with who have experienced injuries or other disabilities—such as specially designed hand controls for a tractor—can also help those with chronic pain. For example, individuals with pain may also have weakness or balance difficulties that make it hard to climb on and off a tractor. Given the height and location of the operator’s seat, added steps and hand holds can help
increase the safety and usability of farm tractors. Commercial lifts can help these farmers gain access to high operator platforms in combines or grain trucks.

There are several commercial devices to help with the proper maintenance of grain bin storage that are particularly helpful to those with back injuries. For them, climbing the bin ladder or stairs to open the cap when filling or aerating the bin may be difficult or impossible. These farmers can avoid additional injuries with special treads for shop flooring, steps, and ladder rungs.

On page six, you can read about how one AgrAbility group is considering how trained service dogs might help with farming tasks.

The Roots of AgrAbility

On June 18, 2008, the Farm Bill was reauthorized by Congress, securing another eight years of funding for AgrAbility. To mark this occasion we are looking back on the past 17 years of the USDA’s funding of AgrAbility and our combined efforts to assist people with disabilities involved in production agriculture and their families.

It is well known that farming is one of the most dangerous occupations in the United States. It was in 1944 that Franklin D. Roosevelt signed the first National Farm Safety Week proclamation, which brought more awareness to safety issues on our nation’s farms and ranches.*

Every president since then has supported this proclamation. Safety standards for farm equipment have been vastly improved and many private and public organizations are now dedicated to improving farm safety and health. Still, nearly 700 farmers and ranchers die in work-related incidents each year. Another 80,000 workers sustained disabling injuries from work-related incidents in 2005.*

The USDA National Agricultural Statistics Service estimates that more than 200,000 farmers, ranchers, and agricultural workers experience lost-work-time injuries and occupational illnesses every year, approximately five percent of which have serious and permanent results. Off-farm incidents and health conditions disable thousands more farmers each year.

Based on nationwide data from the Census Bureau and the Bureau of Economic Analysis (2000), approximately 387,900 agricultural producers could be affected by disabilities and chronic health conditions. Today, like 17 years ago, there is a continual need for the work done by AgrAbility.

Leadership for the National AgrAbility Project was recently transferred to Purdue University’s Breaking New Ground Resource Center, described at http://agrability.org. Resources and information are also available at www.agrabilityproject.org through the University of Wisconsin (which led the national AgrAbility from 2000 through 2008.)
Living with chronic pain can be tough, even when the most strenuous part of your daily routine is walking to the car. For farmers and ranchers, physical labor is part of life every day. The Utah AgrAbility program helps some of them handle the challenges of living with pain while living on a farm.

Margaret Page worked full time and ran two ranches until 1998, when she retired from her day job to take care of her ill husband, Rex. She continued to run a 150-head cow/calf ranch, but the toll on her body was too much, and a few years ago her doctors advised her to retire from farming and move him to a long-term care facility. “I wish we had thought to buy long-term care insurance,” she said. Despite selling off her cattle, she went into debt trying to keep up with medical expenses. She turned to AgrAbility for help preserving her health and saving her farm. “I knew I couldn’t do it any more,” she said. “I got on the Internet and looked for help, and that’s how I found AgrAbility.”

Page has chronic pain from fibromyalgia, along with many other health problems from almost 71 years of physical work. “My back is shot, my knees are shot, my hips are bad, and I have trouble with my feet,” she explained. Although she has access to excellent doctors in Salt Lake City, Nephi, and at the University of Utah, sometimes it’s difficult getting everyone’s schedules in sync. Ten years ago, she put off a planned knee surgery when Rex got sick, and even regular appointments are sometimes difficult when the doctor gets behind schedule. “It’s a long drive, and a few times I couldn’t see the doctor when I got there,” she said.

A former dairy farmer, Page switched to raising meat cattle in 1978, but always had jobs outside the farm too. Her career at the post office was convenient because the office shut down for two hours at lunchtime, allowing her to come home and get some work done on the farm. “Then I’d come back and work the farm at night,” she said. An 18- or 20-hour day was not unusual for her. “I baled lots of midnight hay, believe me,” she said.

When she had bad days, she tried to keep moving. “Sometimes I crawled when I got up in the morning,” she said, “until I could limber up.” When she became postmaster of a nearby town, she used her desk job as a break, saving her physical energy for farm work.

But she is sometimes nostalgic for those hard days. “Since the doctors told me I couldn’t take care of Rex or ride every day, I think I’ve gone downhill,” she explains. “I think my body has rebuilt as much as it could and now I need to get my strength back.”

But since she became involved with AgrAbility and has been working to get back to her normal life, Page has felt more optimistic and energetic. An emergency on her land had her literally back in the saddle recently, looking for signs of a missing horse. “I rode six and a half hours the other day,” she said. “I was surprised I could do that, but it felt good.”

Independent and Hard Working

Luke Petersen, Utah State University AgrAbility program manager and a farmer himself, says that many farmers don’t ask for help until they’re in a crisis. “People in farming want to be independent, work hard, and be respected for their accomplishments,” he said. When health problems interfere with their work, they try to get by on their own as long as possible. “Farmers are used to fixing things right now with baling wire and twine,” Petersen said. “They’re not as comfortable filling out paperwork and waiting for something to happen.”

Page has been working through paperwork to get financial help for her farm. “I would like to get back to running the farm,” she said. “It’s what I worked my whole life for.” Even though her farm frequently lost money, she was proud of what she accomplished there. “When I sold the last of my herd,” she said, “[the broker] told me those were the biggest and fattest cattle to go through Salina in history.”

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Adaptations for Cooking and Shopping

Health problems have changed Page’s lifestyle. She moved from her large ranch in order to have more neighbors nearby, but she still has trouble getting out of the house when heavy snow blocks the doors and walkways.

Because she has trouble walking and can’t shop in the grocery store, Page shops in a warehouse club store that has motorized carts. She frequently buys meals instead of cooking. “I try to buy one meal a day and split it up, to make it last,” she explained. “That’s my ‘extravagance’.”

Still, she is apologetic about taking these shortcuts. “I had to replace my horse trailer, because I couldn’t load it myself,” she said—adding that the old trailer was last new in 1979.

What would make her happy is to find a way to make money from her farm. “I worked my whole life, sometimes two jobs at a time, to buy this farm. I think it would kill me if I had to give it up,” she reflected.

And there may be something to that sentiment. Farmers who can’t work sometimes think they don’t have any worth. According to Petersen, “a lot of people tell the same story: ‘As soon as Grandpa quit going out on the tractor, he was dead within six months.’ When you live on a farm, there’s no separation between work and leisure time. You’re never off the job,” he said. “It’s part of your identity.”

Making Farm Work Easier

But the AgrAbility program is not just for people in crisis. When involved early, AgrAbility can help people keep working as long as possible by making farm work easier.

Kuedell Jensen got involved with AgrAbility shortly after learning he had arthritic spondylitis, which causes spine pain and stiffness. At the time, the program was just getting started in his area, but a few years later Luke Petersen called Jensen to see how he was doing. “He came by the farm and looked at the equipment I was using,” Jensen explained. “He got me some steps for my tractors, and he also recommended that I get a certain type of seat cushion, which has helped,” he said.

Jensen runs a 300-acre farm that provides hay for his 30-head herd of cattle. He also works a full-time job driving construction trucks to help support his farm, which means he gets up by 5 a.m. to feed the cattle before going to his day job at 8 a.m. “This was my father’s farm, and I was born and raised on it,” Jensen said. Since his brother chose another career path, Jensen runs the farm on his own, saying “If it gets done, I’ve got to do it!”

Jensen can still do most things on his farm with little trouble—but even things that are difficult must get done, he said. “If I have to get down on my hands and knees to do some work, I’ll have a devil of a time getting back up,” he explained. He hopes that the AgrAbility program will help him continue running his farm for a long time to come.

“Luke told me that repetitive work like baling hay would be hard on me, so I switched to a bigger baler,” said Jensen. “It really saves me a lot of work. Now, instead of loading 30 bales of hay to feed my cattle, I use two 2 ½ ton bales.”

An Aging Population

Petersen believes that this kind of help will become even more important as the farming population continues to get older. Family farms aren’t profitable enough to keep many young farmers on the land, and the cost of starting a farm is so high that new farmers are very rare. “The baby boomers are aging, and young people continue to choose higher paying occupations away from the farm,” Petersen explained. He cites the latest census of agriculture in Utah, which shows that in the last five years the average age of farmers in the state increased about 4 years, to age 57.4.

Even with increased attention on farm safety, years of farm work takes a toll. “Although no farmer would admit it, the work gets tougher and your body starts to break down as you age,” Petersen said. “This program is going to be needed more and more in the future.”
Some ideas are meant to come to life, and that’s what has happened in the case of the PHARM™ Dog Project.

Jackie Allenbrand is a farm wife who always had a love for dogs. When she joined the Missouri AgrAbility team in 2005 as an AgrAbility Rural Outreach Specialist she was already thinking about how the animals she loves could help make life easier for farmers with disabilities.

The Missouri AgrAbility Program helps farmers, family members, and workers that may have a disability, disease, or disorder to stay on their farms.

PHARM (Pets Helping Agriculture in Rural Missouri) was born when Allenbrand asked the question, “If service dogs can help persons with disabilities in the general population, why can’t a service dog be trained to assist farmers with disabilities in their daily lives and chores on the farm?”

Allenbrand knew that service dogs can be trained to do a variety of things. In considering farmers, she thought that a dog might help retrieve tools, open a latch gate system, retrieve boots and gloves, open doors, herd, or even stand firm to brace a farmer who needs help getting from sitting (or kneeling) to standing. A dog could also learn to go for help, when needed, for a farmer working in the field or anywhere on the farm.

Organizations Join Together for Support
Missouri AgrAbility is a collaboration between the University of Missouri Extension, SIL (Services for Independent Living), and MERIL (Midland Empire Resource for Independent Living).

To add a new twist to the occupation of service dog, Allenbrand got help from Bev Maltzberger, MERIL Board Member and AgrAbility Coordinator for the NW Region. The PHARM initial pilot project was funded with a $25,000 grant from the Institute for Human Development at University of Missouri-Kansas City.

The goal of the PHARM Dog pilot project is to identify and work with a focus group of farmers with disabilities and determine their needs on the farm.

The first step was a needs survey to see exactly how a service dog would should be trained to help farmers. Based upon that input, a specific curriculum will be
developed and dogs trained. This part of the pilot project was started in early 2009, when guidelines were established.

Once the project has been tested and proven, Allenbrand hopes that PHARM will become part of the Missouri AgrAbility Project and eventually a national AgrAbility program.

Collies and Cattle

Three farmers have expressed interest in being part of the pilot PHARM Dog Program. Two farmers are interested in Border Collies for herding purposes and one is interested in a service dog for help on the farm. Allenbrand is currently working with a Border Collie trainer who has 45 years of experience working with this breed in herding sheep and cattle.

To understand how service dogs operate, Allenbrand has consulted dog trainers that place service dogs with clients with many types of disabilities, including some who need a low blood sugar alert. They also train dogs for autistic children.

Kristy, a dog who lives on the Allenbrand farm, is the PHARM “demo” dog. Kristy travels with Allenbrand to do presentations for businesses and organizations that want to learn more about the PHARM Dog Program.

While funding for this pilot project is being provided through a grant from the Institute for Human Development, additional funding is always needed to help the program grow and to be able to help more farmers.

For more information or questions about the project, contact Jackie Allenbrand at 816-279-8558 ext. 1026, jackiea@meril.org, or allenbrandj@missouri.edu or write to 4420 South 40th Street, St. Joseph, MO 64503.

Jackie Allenbrand and her dog Kristy demonstrated her skills at the Hundley Whaley Research Farm in Albany, Missouri, one of the University of Missouri’s research farms. That day they talked with 300 students.

Growing Well

It was clear they couldn’t come to us, so with a grant from Medtronic Foundation, we visited 10 states to present Growing Well with Pain.

The response was amazing! Many traveled long distances to attend. They were so appreciative that someone would make the effort to come to them with information that might help them reduce their sense of suffering. But we were still missing some of those who needed to have access to this information. So we went back to Medtronic Foundation and with their support were able to videotape the presentation and send it to all those who are part of AgrAbility. We have also posted the talk on our ACPA Web site.

While the trips I took for AgrAbility were challenging geographically, the payoff was far more than I expected. With each talk I gave, it was clear that the endeavor was worthwhile and long overdue. I met many wonderful people along the way who left a lasting impression. All I can say is THANK YOU to every person who works hard day after day to ensure that we have food to eat. Thank you for allowing me to come into your lives and for sharing your stories with me.
How do you properly dispose of unwanted or expired prescription drugs, especially oral and transdermal opioids? There is no simple answer. Discovery of trace amounts of pharmaceuticals in the water systems, along with the increased incidence of prescription drug abuse, has brought this issue to a point of concern among patients and health care professionals.

To provide a clear direction, the new federal guidelines recommend disposing of most medications by:
* Mixing them with unpalatable substances (coffee grounds, kitty litter, etc.)
* Removing any personal or identifying information
* Placing them in a nondescript sealed container, and
* Disposing of them with your regular trash.

There are some exceptions for which the manufacturer of the drug recommends disposing of the drug in the toilet. These drugs include: Actiq, Avinza, Barcode, Daytrana, Demerol, Diastat, Dilaudid, Dolophine, Duragesic, Estrogel, Fentora, Ionsys, Opana, OxyContin, Percocet, Suboxone, Subutex, Tequin, Tyzeka, Videx, Xyrem, and Zerit.

For the drugs on this list, transdermal preparations should be folded in half—so that the sticky side sticks to itself—and flushed down the toilet. If you are ever uncertain how to dispose of an individual drug, contact the manufacturer for advice.

While the primary concern with the disposal of prescription drugs is possible environmental hazards, you should also be concerned about your prescription medications ending up in the wrong hands, a process known as drug diversion. Drug abuse and diversion are steadily on the rise in the United States. By properly disposing of socially desired substances, you will help to reduce this potential problem.

Do Not Use After This Date
A drug’s expiration date is not a date after which the medication has “gone bad.” In fact, it is the date after which the manufacturer can no longer guarantee the effectiveness of the drug. While most drugs lose their potency after the expiration date, most do not become toxic or dangerous.

The only proven exception to this is tetracycline, an antibiotic that has been found in tap water. While this creates a potentially toxic agent in the water supply, there is also concern that resistant organisms may arise due to persistent exposure to low levels of antibiotics in the environment. A variety of other antibiotics and commonly used daily medications are also found in tap water. The proper disposal of all of these medications will help to alleviate this problem.

When pharmaceuticals are detected within water systems, it could indicate chronic exposure to these substances, the point when safety issues become a concern.

Pharmacies and hospitals must comply with other regulations for proper disposal of medications, but these regulations do not extend to the consumer. You should also take advantage of any community pharmaceutical take-back programs that allow the public to bring unused drugs to a central location for proper disposal.

By informing the public of the appropriate disposal techniques, the healthcare community hopes that unintended exposure to medications, and drug diversion, will decrease.

Alyssa Haraczy and Meredith Kolbas are PharmD candidates, 
Duquesne University Mylan School of Pharmacy, Pittsburgh, PA. 
The article was reviewed by their professors before publication.

References:
On March 19, 2009, comparative effectiveness research (CER) was in the national spotlight, as President Obama signed an economic stimulus bill including an unprecedented $1.1 billion to fund more CER.

CER—also called health technology assessment—has been used by health insurance companies for some time to weed out “inferior” treatments by determining which ones work the best.

Now, policymakers hope that CER will encourage better decisions by payers, providers, and patient/consumers to reduce healthcare spending without compromising the quality of care. But for people with pain, the question remains, “how will this research, based on the average effects of treatment on patient populations, be used to make very personal treatment decisions about my healthcare?”

Understanding CER
Comparative effectiveness research is defined by the Congressional Budget Office as “rigorous evaluation of the impact of different options that are available for treating a given medical condition for a particular set of patients/consumers. Such a study may compare similar treatments, such as competing drugs, or it may analyze very different approaches, such as surgery and drug therapy. The analysis may focus only on the relative medical benefits and risks of each option or it may also weigh both the costs and the benefits of those options.”

Bottom line? CER seeks to find out which treatment works best for a given medical condition.

CER offers an opportunity to greatly improve the quality of care consumers receive through our healthcare system, but it is critical that these research findings be treated as helpful information to aid in healthcare decision making between a patient and physician and not dictate “one-size-fits-all treatment.” As advocates who represent the interests of people with chronic conditions, we know that everyone should be treated individually based on needs, health status, history, and other individual factors.

Advocating for Solid Decisions
There are some concerns that CER findings would be used to make healthcare coverage decisions that would ultimately take away decision-making authority from patient/consumers and their doctors. To prevent this from happening, advocates have urged policymakers and those using the research to not let CER become the sole determinant of which services or treatments should be provided or covered. This advocacy has been met with some success.

Additionally, people with chronic pain and other illnesses must play a meaningful role in designing, carrying out, and interpreting CER. They bring valuable perspectives and expertise to discussions regarding research priorities and how clinical research should be conducted. As the individuals most personally and forcefully affected by the outcomes of this research, they should be considered the primary audience and ultimate end users of the information created by CER. Their voices need to be heard in discussions to determine how comparative effectiveness research should be conducted.

Collaborating for Engagement
The National Working Group on Evidence-Based Health Care (the Working Group) is a collaboration of patient/consumer organizations, professional societies, providers, researchers, and other interested stakeholders who want to stay abreast of the developments and initiatives in evidence-based healthcare. Since January 2006, the Working Group has sought to educate and engage all these groups and stakeholders.

We believe that it is vitally important that patients and people with chronic medical needs be well-represented in national discussions about comparative effectiveness research. We also believe that there should be strong support and resources to help them effectively participate in driving how the $1.1 billion in CER funding is spent.
How to Complain

Unsatisfied with the medical care you’ve received? Did you have problems during your last hospital visit? In a recent advice column, Dr. Carolyn Clancy, director of the Agency for Healthcare Research and Quality, offers suggestions on how to complain and be heard.

Dr. Clancy suggests you start with the hospital’s own patient liaison office. State and federal government agencies and national health organizations also advocate for consumers in disputes with healthcare facilities. There is additional advice for those who feel they are being discharged from a hospital too soon and for people who discover billing errors.

Those who are covered by Medicare can file complaints about medication or surgical errors and inadequate treatment through their state’s Quality Improvement Organization (QIO). You can find your QIO by calling 1-800-MEDICARE. You can read the entire article online at AHRQ’s Navigating the Health Care System. http://www.ahrq.gov/consumer/cc.htm

Methadone Misuse: A Complex National Concern

Methadone is a commonly known drug used to assist addicts in their recovery from abuse of habit-forming drugs or prescription medications. Methadone is also prescribed to treat moderate-to-severe chronic pain.

The ACPA is participating in a nationwide educational campaign about the safe use of methadone. Follow Directions: How to Use Methadone Safely is sponsored by the Substance Abuse and Mental Health Services Administration (SAMSHA) and the Food and Drug Administration (FDA), agencies of the U.S. Department of Health and Human Services (HHS).

Methadone’s use as a pain reliever has dramatically increased over the last several years. According to a 2008 federal government report, methadone has been associated with an increase in deaths and emergency room visits.

People who take methadone normally feel relief within four to eight hours. However, a single dose of methadone can remain in the body anywhere from eight to 59 hours. As a result, methadone may build up to toxic levels if taken too often, in too high an amount or with other medications.

“Used as prescribed, methadone is a safe and effective drug,” said Douglas Throckmorton, M.D., Deputy Director of FDA’s Center for Drug Evaluation and Research. “Prescribing methadone is complex. However, with proper education to physicians and patients, the risk of misuse or abuse can be minimized.”

To download free copies of the educational materials, please call 1-800-662-HELP or visit www.dpt.samhsa.gov/methadonesafety.

Follow Directions: How to Use Methadone Safely

Used as prescribed, methadone is safe and effective.
ACPA Update

ACPA Advocacy Training
Ensuring that the voices of people with pain are heard on the issues that have an impact on their care and lives is part of the ACPA’s mission. On May 16 and 17, 2009, the ACPA held media and advocacy training for group facilitators and regional directors, thanks to a grant from Purdue Pharma.

At this session, participants received updates on key issues including the FDA’s proposed Risk Evaluation and Mitigation Strategies (REMS) regulations and step (or fail-first) therapy, grounded in evidence-based medicine. In addition, they learned how to speak effectively to the media and how to develop grass-roots support for the interests of people with pain and their families.

Facilitator Training Video Available
Strong support groups are at the heart of the ACPA’s efforts to empower people with pain. Now, we have augmented The Facilitator’s Guide with a videotaped training session, led by Penney Cowan.

Filmed when Penney trained graduates of the Kaiser-Permanente pain program to begin their own support groups, this DVD is available to any ACPA facilitator through the national office. Just contact us at 800-533-3231 or acpa@pacbell.net.

U.S. News Recommends ACPA
The ACPA was mentioned in an article posted earlier this year on the U.S. News and World Report Web site, “Finding Effective Treatment for Your Chronic Pain” discusses researchers who are studying the effectiveness of alternative ways of delivering pain medications. The article recommends that readers contact the ACPA to get advice on selecting a multidisciplinary pain management programs. You can find that information at www.theacpa.org/people/pain_program.asp

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

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Since 2005, Mary Jane Bent has been an ACPA board member and official ACPA photographer. So we are expressing her contribution through some of the photos she has taken at ACPA special events over the years. “Through my lens I've tried to capture the devotion of all our board members, particularly people like Penney, Nicole Kelly, and Steve Feinberg,” says Bent. “It has been remarkable to witness the level of awareness that they, and so many others past and present, have brought to the issue of chronic pain. They've established a considerable network for people with pain, people who need that interaction to help them maintain their daily activities, inner strength, and spirit.”

A Pittsburgh resident, Bent is manager of the Photographic Services within the Center for Instructional Development and Distance Education at the University of Pittsburgh. She also does freelance photography and teaches at Pittsburgh Filmmakers. Formerly director of photography at Allegheny General Hospital, she has also taught at the Pittsburgh Center for the Arts and Carnegie Mellon University.

This is part of a series of articles intended to give readers more insight into the interests and contributions of ACPA board members.
Facilitator Forum: Guidelines for Support Groups

by Susan Gold

When groups of people come together to discuss such emotionally charged topics as living with chronic pain, operational and conduct guidelines are important to let members know what to expect and to avoid negative behavior.

For your support group, you can publish the guidelines in a newsletter, have them on display near the sign-up sheet, or read them at the beginning of each meeting. Here are guidelines that have worked with support groups.

1. The mission/purpose of the group is to provide a safe place where people with chronic pain can support one another, develop friendships, share ideas and thoughts, learn about their conditions from professionals and each other, and learn coping skills in a nonjudgmental and caring atmosphere.
2. All members are expected to show courtesy toward other members. This means that members do not interrupt or talk while someone else is expressing his or her views.
3. Members are encouraged to discuss their problems and situation, but not to dwell on them. The goal of the group is to offer support and to focus on finding solutions and ways of coping with problems.
4. Everything said at the meeting is to be considered confidential.
5. Group members respect others' feelings and do not attack, criticize, nor judge another member's views.
6. No one is coerced into talking; all who wish to talk are given a turn. No single member is allowed to monopolize the meeting.
7. The group leader is not the expert; all members are experts in chronic pain and are encouraged to take part in the meeting.
8. The group belongs to all the members and everyone is responsible for its success.
9. We help others as we ourselves have been helped.
10. Meetings begin on time and end on time.
11. The group does not take the place of medical and/or other professional health care. As such:
   * Members do not prescribe treatment or diagnose symptoms.
   * Information that is provided is not necessarily endorsed or recommended by the group or its leaders.
   * The group does not promote specific goods or services, nor does it allow salespeople to pitch products to the group.
   * Each member is personally responsible for assessing the information presented during the meetings.

Other Tips for Group Leaders

As a group leader, your aim should be to keep meetings upbeat, focusing on coping skills and ways to deal with chronic pain. Encourage people to talk, but don’t put people on the spot. Sometimes a person who is uncomfortable talking in front of the whole group will interact with others during a break.

Make people to feel like it's their group, so don’t be bossy, just be a helpful guide. Certainly, allowing people to talk back and forth can be informative and foster interaction. Discourage any comments that are harsh or attack another member's ideas. Encourage members to be supportive in their comments and suggestions. In this way, you are helping to build relationships and share information.

Susan Gold founded the Chronic Pain Support Group of Southern Maine (Old Orchard Beach) in 1993. In 2008, she stepped down as group leader but continues as a member and manages their Web site www.painsupportgroup.org. Any facilitator may send submissions to this column to Editor, ACPA Chronicle, ACPA@pacbell.net.

Comparative Effective Research

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How can this happen?

1. Patient/consumer groups must be included in developing CER priorities and research design to ensure their needs are represented. Public comment periods are valuable mechanisms for communicating these perspectives to decision makers.
2. These groups must assist in translating and disseminating findings from CER so information is accessible and user-friendly. Support groups and advocates know best how to reach out to their members and are positioned to tap into existing communication tools and media.
3. These groups should advocate to ensure that CER does not inhibit physicians’ autonomy to make the best decisions for those under their care.

Evidence-based healthcare balances three indispensable components: scientific evidence, the clinical expertise of practitioners, and an individual's health needs and values. In practice, scientific evidence, like CER, should inform and support individualized healthcare decisions made together by people and their healthcare practitioners.

The Working Group hopes to prompt all stakeholders to engage in these discussions to preserve decision-making authority between all healthcare consumers—including people with pain—and their physicians. For more information about the Working Group, please visit: www.evidencebasedhealthcare.org or contact Hazel Moran at hmoran@mentalhealthamerica.net.
Tributes

In Memory of
Lisa Laird
Mr. and Mrs. Bob Wyatt, parents
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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.