Living with pain is difficult. Looking to traditional medicine may not provide the relief so many people with pain seek. While medication, surgery, procedures and other conventional modalities may be helpful with chronic pain, we often need to look beyond them to a road less traveled in healthcare: Complementary and Alternative Medicine (CAM) therapies.

Rarely are we given recommendations to receive acupuncture for a cold, or massage therapy for the flu, yet CAM therapies are becoming essential components of our personal regimen as we move on our journey from patient to person. Even things such as art therapy and music therapy are out of the “normal” realm of health care.

But when you think about it, living with chronic pain is also far from a normal state. While traditional interventions may help ease some of the pain and suffering, there is still an additional level of pain that cannot be relieved. The American Chronic Pain Association (ACPA) has helped many people to understand that it is possible to live a full life in spite of the pain if they take an active role.

As with all the components that the ACPA has recommended, alternative therapies are ones you may want to add to your tool box.

Although there is no single cure for chronic pain, putting together a number of proven, effective, CAM therapies may actually help to reduce your sense of suffering while increasing your function and improving the quality of your life. There are many roads to explore when looking for ways to manage pain and sometimes it is the road less traveled that might actually help you on your journey from patient to person.

In this issue we will travel with researchers, people with pain and support group facilitators who have explored therapies such as exercise, meditation, and biofeedback to manage their pain. Please read on to discover new roads of treatments that you may not be familiar with.
Complementary and Alternative Medicine (CAM) can significantly aid those seeking a fuller life despite chronic low back pain (cLBP). With so many choices within CAM and even more claims, where does one begin? What is likely to help? How much help is realistic?

According to the National Center for Complementary and Alternative Medicine (NCCAM, part of the National Institutes for Health), all of the following CAM therapies have “promising evidence of potential benefit” for those with cLBP: massage, spinal manipulation, acupuncture, progressive relaxation, and yoga. Therapies with “limited, mixed, or no evidence to support use” include prolotherapy and herbal therapies.

What is CAM?
CAM are those therapies that are added to or are in place of “conventional” medicine. “Integrative medicine” seeks to combine the best of conventional treatment and CAM for a particular individual. CAM may be grouped in various ways:

Evaluating CAM or Conventional Treatments
Patients in pain want effective and safe therapy. They may not care whether it is CAM or conventional medicine. Many conventional treatments and most of CAM are yet to be adequately studied for effectiveness. For those therapies that have been studied, one should first assess the methods used to analyze the particular therapy.

The strongest research designs are Randomized Controlled Trials (RCT) with participants unaware if they are receiving the experimental or control therapy—a “blind” study. The control comparison group may be “Usual Care” (UC) or placebo treatments. Blinding should also be done for the researchers who measure outcomes (results). Without proper study methods, outcomes may be due to chance or bias (swaying from the true results) instead of being an effect of the experimental treatment. Much of the older CAM research relied on weaker scientific designs, such as non-blinded participants or “Case Series”, so that results may be biased and not reproducible.

Note that yoga is listed under Mind-Body Medicine, yet it is part of the Whole Medical System of Ayurveda as well. Acupuncture is not only practiced as a distinct Body-Based Therapy but also as part of Traditional Chinese Medicine as a whole.
If the methods of study are sound, one then should assess the significance of the results. Strong methods may produce one of these types of results:

❋ Clinically significant decrease in pain (greater than a 20 point decrease in pain on a 100 point scale)
❋ Statistically significant decrease in pain (less than a 20 point decrease; a mathematically but not clinically appreciable change)
❋ No difference in pain (95 percent “Confidence Interval” (CI) of result of experimental therapy is overlapping with CI for control therapy)

These same categories can be applied to non-pain results such as increase in function or in Quality of Life (QoL). An example of a clinically significant increase in function would be more than a two- to three-point improvement (out of 24) on the Roland Disability Questionnaire (RDQ). Also, one should consider the duration of effect; many CAM treatments are only effective during ongoing administration of the particular CAM, however, some provide long-term improvements.

Finally, in evaluating CAM, if studies have sound methods and clinically significant results, one should consider the pros and cons of applying that specific CAM. Application questions are driven by the values and resources of the individual with chronic pain. For example: is it available locally, is it acceptable, what are the side-effects and how much it costs, to name a few.

**CAM Therapies for Chronic Low Back Pain**

Three Body-Based Therapies have at least moderately strong methods and results for reducing pain: massage (Cherkin, Sherman et al. 2011), spinal manipulation (Rubinstein, van Middelkoop et al. 2011) and acupuncture (Vickers, Cronin et al. 2012). Any of these three provides a reasonable opportunity to produce a clinically significant decrease in pain at least a little but not to cure it. The decrease in pain usually continues for as long as the treatments are continued, typically around 10 weeks.

The specific type of massage/manipulation/acupuncture did not seem to be crucial, nor the specific type of practitioner. None of these three are likely to markedly improve one’s function. Choosing between treatments depends on the answers to the application questions above. While all are reasonably safe, rare, serious complications have occurred with acupuncture. Costs for one course of any of these would be hundreds of dollars in out-of-pocket expenses.

Of the other Body-Based Therapies, prolotherapy (Dagenais, Yelland et al. 2007) has not improved nonspecific CLBP, but the Alexander Technique (AT) (Little, Lewith et al. 2008) has. For AT, a large, well-done study was performed with patients from general practice clinics. The participants were divided into eight groups: four with exercise and four without. Each of these four was made up of one each of usual care, 6 massage classes, 6 classes of AT or 24 classes of AT. After one year, those individuals with CLBP who learned AT through 24 sessions over 28 days, had, on average, 20 fewer painful days compared to the usual care control group, and more than 9 fewer painful days compared to massage with or without exercise.

Some forms of CAM Mind-Body approaches, such as deep breathing and progressive relaxation, are already accepted as part of conventional medicine, including the successful Cognitive Behavioral Therapy for chronic pain. Mindfulness training (Cramer, Haller et al. 2012), proven to be moderately helpful in affecting anxiety disorders, has not yet produced clinically significant changes in pain or function for CLBP—if one accounts for methodological flaws such as not accounting for patients who dropped out of the studies early. The focus of mindfulness is adopting a nonjudgmental attitude of accepting “what is.” Studies did show increasing “acceptance” scores—findings which may be meaningful for some concurrently suffering from anxiety.

**CONTINUED ON PAGE 4...**
Yoga studies have mostly been of poor quality (Posadzki, Ernst et al. 2011), however with Iyengar Yoga, Williams and colleagues (Williams, Abildso et al. 2009) demonstrated promising trends in improved pain and function after 24 sessions over 12 weeks. Yoga, like the Alexander Technique, may be an empowering self-care practice for those with chronic pain, promoting independence from ongoing clinic-based therapies.

Herbal therapies have not yet proven their worth for cLBP. In a methodologically strong RCT, Wilkens (Wilkens, Scheel et al. 2010) and colleagues showed no improvement with glucosamine sulfate. A small trial of a German product containing harpagoside (Chrubasik, Junck et al. 1999), a.k.a. Devil’s Claw, reduced acute exacerbations of cLBP. However finding a similar product in the United States is complicated by the lack of standards for its preparation as the Food and Drug Administration is not allowed to oversee these compounds that are foods and not drugs.

Energy Medicine has the least evidence basis to date. Static magnets have not lessened pain. Reiki has been tried in several low-quality studies for acute anxiety states, but it yet to be demonstrated in an RCT for cLBP. The same is true of Healing Touch.

**Which CAM is Worth Trying for cLBP?**

The evidence for massage, spinal manipulation, or acupuncture to decrease pain after a few months is better than that for frequently used opioids (Portenoy and Foley 1986). An average dosage of 73 mg. of Morphine Equivalents Daily (MED) was not statistically different from placebo for pain in a systematic review of RCTs in cLBP (Martell, O’Connor et al. 2007). None of these three Body-Based Therapies have the safety risks of accidental death, which is approximately doubled in patients taking more than 50 mg. MED (Bohnert, Valenstein et al. 2011). Choosing any one of these three would be very reasonable, based on preferences, availability, and costs.

Cognitive Behavioral Therapy (CBT), which includes deep breathing and progressive relaxation training, has consistently helped those with cLBP. CBT, along with the Alexander Technique and probably yoga, all provide training that usually improves function and lessens pain for extended periods. Once any or all of these are learned, a person can continue on his or her own and does not need to return continuously to a CAM practitioner.

Effective CAM should be seriously considered as part of a treatment plan to live a fuller life in spite of cLBP.

Michael Saenger, MD, FACP, is Leader of the Task Force for Opioid Safety, and Co-Chair, Integrated Pain Management Working Group, Atlanta VA Medical Center. He is also Fellow, National VA Quality Scholars Program; Assistant Professor, Emory University School of Medicine and Consultant for Chronic Pain Management, Grady Health System.

**Editor’s Notes:**

Graphic from NCCAM Summary:

Prolotherapy describes a procedure for strengthening lax ligaments by injecting solutions directly into torn or stretched ligaments or into a joint to create scar tissue in an effort to stabilize a joint.

The AT teaches people how to stop using unnecessary levels of muscular and mental tension during their everyday activities.

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Some alternative therapies are more closely related to art than to medicine. Currently the ACPA is working on a project called The Art of Pain Management, which uses both art and music to help people manage pain.

Recently, one of our peer support group facilitators asked her members to try this experiment, testing how music affects pain levels. She asked each member to take 15 minutes out of their day to listen to instrumental music, choosing a recording without words, of a slow to medium tempo.

They were instructed to find a quiet place and to rate their pain before and after listening to the music, using the zero to 10 scale. The results were that 60 percent of the group felt less pain after listening, while 80 percent felt more relaxed. Watch for more information about this project in the September issue of the Chronicle.

**If you have incorporated the arts—music, poetry, painting, dance, or crafts—into your pain management routine, we would like to hear about it and possibly feature your story in our newsletter.**

Send your story (600 words or less) to:
The ACPA, PO Box 850, Rocklin, CA 95677
Fax: (916) 632-3208 • Email: ACPA@theacpa.org
Young People Connect, Share Feelings on GrowingPains.org

by Maggie Chesnut, Community Manager, GrowingPains.org

In late 2012, the ACPA launched GrowingPains.org, a fresh and interactive social networking website for people with pain. Ten years have passed since Growing Pains was born, so I like to imagine that the group is entering its teen years. It began as an online support group for youth with chronic pain and illness. This was back before Facebook, when everyone used AOL and AIM.

I was 14 years old and desperately wanted to connect with my peers who lived with pain. I spent many nights in high school on my family’s computer emailing kids as young as eight, and often their parents as well, offering any support and insight I could muster. Through these connections, I found meaning in my pain. Still, I wanted to offer more to my peers who felt they had nowhere else to turn.

My original intention for Growing Pains was to introduce youth of similar ages or diagnoses so that they could support one another through email. However, the participants were transient and I found it difficult to coordinate lasting connections online. Through discussions with Penney Cowan, executive director of ACPA, it became clear that youth with pain needed a space where they could find one another. This could be a place where the invaluable resources that the ACPA developed over the past 33 years would be presented in age-appropriate and engaging ways. Thanks to social networking and Penney’s undying dedication to all members of the chronic pain community, this vision has become reality.

Express Yourself and Explore Resources
For me, GrowingPains.org is literally a dream come true. The site has blossomed into a living environment where connections between users can grow organically. The bubbly and colorful home page appears simple, but a moment of exploration will reveal the depth of resources just beneath the surface. Users grow their own tree by selecting a “WordLeef” to describe their current mood. Did you catch the spelling error? The site’s designer is a person with pain who chose to reverse the word “feel” to create the leefs on GrowingPains.org. This level of detail is consistent throughout the structure and content of this unparalleled new resource.

GrowingPains.org offers more interactive features than I ever imagined was possible! Users can make their own avatar, upload pictures and video, write their own private or public pain logs, add WordLeefs, answer questions, explore innumerable resources, and comment on everything. This is a site you can get lost in. If you haven’t visited yet, check out the video on the home page or register and play around. It sure has come a long way from Instant Messaging!

GrowingPains.org is open to anyone age 13 or older. While it was designed with youth in mind, fifty-five users older than 13 have registered. Clearly the site appeals to a wide age range, so we welcome anyone who feels they will benefit by joining the community.

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Facilitators Promote Holistic Approach to Pain Management

by Erin Hart

For many thousands of years, people and providers around the world have embraced CAM practices. One belief underlying many CAM practices is that to effectively address a health issue, we should treat the whole person and not just the point of injury, as the injury affects all adjoining parts.

Although not meant to replace modern medical treatments, CAM is used by many individuals with chronic pain to enhance the relief gained by traditional medicine. Vetted carefully, practiced routinely—and most importantly, with a physician’s approval—the techniques can enhance quality of life, as they have done for two ACPA facilitators.

Pursuing Passions Amidst Pain
Penny Rickhoff has never been shy about pursuing her passions. In 1963, she began to study nursing, which she later put aside to work in real estate development. At age 33, she started tennis lessons (a sport she became passionate about), and began walking for exercise. Five years later, she received her pilot’s license and flew to more than 50 countries for both business and pleasure. The experience, she says, gave her a unique perception of life around the world.

What Rickhoff, now 67 and living in Phoenix, Arizona, didn’t anticipate was giving up some of the activities she loved because they made her chronic pain conditions worse.

Although her pain started in the mid-1970s after she turned a mattress, Rickhoff said it was tennis that truly ignited a lifestyle with chronic pain. While playing a doubles game in 1984, her back locked up, causing excruciating pain. She was admitted to an emergency room. Later, a neurosurgeon confirmed the diagnosis of a herniated lumbar disk.

To relieve the pressure and pain from the aggravated disk, and restore a normal gait, Rickhoff had a laminectomy to remove the offending disk. For the year following the surgery, she was pain free and re-exploring her passions, which included playing tennis and riding her favorite horse, Cisco.

In 1985, while grieving the unexpected death of her stepson, Rickhoff became physically ill. She had developed a disk space, a bacterial infection at the site of the laminectomy. Nine months of treatments followed.

Once she healed from the infection, Rickhoff said she underwent lumbar fusion using bone from her hip, which gave her a new lease on life. She was able to play tennis again, but had to give up riding. Life was good for five years, until one day when she was at work for the real estate company.

As she bent down to retrieve several items from the floor, a tall metal filing cabinet fell on top of her—ending her office work for good.

A New Beginning
Not long after, an investment opportunity took the family to Florida, where Rickhoff found a new physician. He referred her to the Upledger Institute International, Inc. in Palm Beach Gardens, Florida, which pioneered the use of CranioSacral therapy, a gentle, hands-on approach that releases tensions deep in the body to relieve pain and dysfunction and improve whole-body health and performance.

Seeking more help, she enrolled at the University of Miami pain and rehabilitation hospital. At this multi-disciplinary pain management clinic, Rickhoff learned about a wealth of alternative treatment methods for her chronic pain, which included biofeedback and acupressure. Many of the pain management skills she learned, unfortunately, were forgotten, until the ACPA became part of her life many years later.

“Without our regular support group meetings,” Rickhoff said, “those effective skills seem to fall by the wayside.”

Having an athlete’s mentality, Rickhoff opted to again experiment with alternative healing therapies. She tried chiropractic, physical therapy, and massage instead of medications. However, during the last 15 years, as her pain threshold began decreasing, she said she needed more.

Her next stop was the Mayo Clinic in 1990. Located near her home, the clinic offered medications, physical and occupational...
therapy, and invasive pain management treatments such as anesthetic and steroid injections, pain blocks, and root oblation. A physician also suggested that Rickhoff join a chronic pain support group, which is how she found the ACPA.

All these methods were helpful to a point, but Rickhoff said the most effective technique was one she learned at the University of Miami clinic: biofeedback. When she practices regularly, she can achieve near-instant relaxation. The technique has been very effective at relieving muscle contraction headaches.

Intrigued with the benefits of alternative therapies, Rickhoff sought out more. She tried acupuncture for several months with a Chinese doctor, whose technique of deeper needle insertion gave Rickhoff measurable relief. She began using biofeedback via a headband with headphones. The device emits sounds that enable the user to slowly relax muscles in the head, face, and neck. As the tension fades, so does the sound.

**Knowledge Sharing**

One technique she has shared at her Scottsdale, Arizona, ACPA support group meetings is guided imagery, which uses the five senses to mentally partake in a relaxing, favorite scene. She reserves the last five to 10 minutes of each meeting to practice this with her group. During her own day when pain starts to creep in, she sits in the sunshine, closes her eyes and uses the technique to relax and help control her pain.

Rickhoff estimates that over the last 15 years, she’s tried a couple of dozen alternative therapies—some that have worked and some that haven’t. Her toolkit includes:

- **Acupressure**—used when Rickhoff suffers from headaches. She moves her index finger along the ridge of her shoulder blade, then applies pressure on her trigger points (muscle knots) until they release.
- **Acupuncture**.
- **LTD 1000**—a device that emits a cold laser light directed at a trigger point.
- **Stim Plus**—handheld monitoring device that uses electrical current to release a trigger point.
- **Tai Chi Chuan**—Rickhoff has been taking lessons twice per week for 16 years and practices daily.
- **Thera-Cane massager**—a curved, wrought iron cane that can be used to place pressure on trigger points in the back.
- **Tush-Cush**—Firm, slanted cushions with a cut-out for the tail bone (the spine is suspended), which relieves pressure. She uses two placed on top of one another for added support.

**Hot and cold modalities** (especially ice packs).

**Various over-the-counter medicated ointments** (camphor and menthol), capsaicin, and patches.

As important as these techniques are to her and others, she is quick to remind everyone that they are not a cure all.

“When you have so many problems going on at the same time, you can’t change your anatomy and cure the pain with all of these alternative treatments,” Rickhoff said. “When you are like me and your spine is degenerating, it’s hard to stop the disease process. These methods are for pain management: to improve circulation, relax muscles, decrease pressure on nerves, and perhaps help delay the deterioration and the effects of aging.

“Effective treatments combine medication and alternative therapies. It’s hard to function when you are in pain, so you need the medications to take the edge off, so that you can use the other treatments. It is similar to trying to teach a starving child to read. You must first tackle the hunger, then the teaching can follow.”

**Living Life Again**

Rickhoff says her combination of treatments have improved her outlook on life tremendously. Although she takes medications to help control her pain, she maintains an active lifestyle. She practices 40 minutes of Tai Chi daily and works out with light weights. She also meets with friends often, enjoys time with her three sons, daughter-in-law, and four grandchildren, and takes pride in her ACPA facilitation role, which she has held for the last 18 years.

“My group has given me a way to give back to society, and I always seem to get back much more than I ever give to the members,” she said. “They bring a whole plethora of helpful information to the meetings—things that each of us can, at times, take to our own healthcare practitioners.

“I share with my groups that everyone can have a happy life using these tools and practicing a positive lifestyle. In addition to managing the physical, psychological, medical, and spiritual aspects, you also need to get out there and socialize and be around others. All the therapy in the world won’t help you if you don’t find a way to interact with others.”

**Life-changing Moments**

Many adults look back fondly on their youthful times at summer camp—recalling the days of exploration, freedom, fun, and friends. For Kathie Hood, 70, of Danville, California, the experience was life changing.
At camp one day in 1961, she slipped on a wet rock, flipped backward and landed on the ground, unconscious.

"About a half hour later, I woke up in a hearse, which, for this small town, actually doubled as an ambulance," Hood said, laughing. "Once I got to the hospital and the doctors ran some tests, they found the force of the fall had pulled the ligaments from my neck, which do not grow back. Ever since then, I have been plagued with pain and problems."

And Murphy's Law.

At age 32, she was in her car, stopped at a red light. The driver behind her failed to stop, hitting her car not once, but three times. As a result of the impact, her neck swelled so much, she said, that "there was no visible difference between my neck and my chin." Doctors put her in a neck brace to provide support, but the device did nothing for the near-constant headaches that the accident aggravated.

At age 48, Hood began experiencing severe pain just below her left elbow and shoulder, which caused numbness in the first three fingers of her left hand. This was related to her neck problems and she eventually underwent surgery to fuse two vertebrae and relieve the pain.

Finally, she was the most pain-free she had ever been. She started to enjoy life and feel healthy again. She embarked on her second marriage. And then the pain returned, this time behind the ear.

She again visited a neurosurgeon, who diagnosed her with a degenerative neck, bone spurs, and stenosis, a narrowing of the spinal canal. Hood underwent two more surgeries: one to fuse parts of her vertebrae and two, a laminectomy on her lower back.

Seeking Alternatives
Although the surgeries were somewhat successful and provided some relief, Hood was tired of the same answer to her chronic pain conditions—surgery. She began investigating alternative pain relief methods that she could use in tandem with pain medications. The process, she said, became very similar to cooking pasta.

"You know when you make spaghetti—after it's cooked for a while, you take it out of the water, throw it on a wall and hope it sticks? That is very similar to trying out alternative pain relief methods," Hood said. "You find something, try it and hope it works. If it doesn't, you move onto something else."

Her first go at alternative therapy involved acupuncture, though she was skeptical at first, as she wasn't sure what it would entail. Her twice-per-month sessions have helped alleviate back pain symptoms and given some relief from bowel problems. Bi-monthly massage has also been helpful, but the expense and lack of insurance coverage means she can only afford this a few times a year.

Hood has personally tested approximately 12 alternative treatments for pain relief. Her tried-and-true arsenal includes:

- **TENS Unit**—For this electrical nerve stimulation device to work, users place sticky electrodes on skin around the painful area. When the TENS unit is turned on, it delivers a light current through the electrodes to the skin and tissues just beneath it. Users feel a bit of tingling—similar to pins and needles. If set high enough, the device can make a muscle twitch.
- **Saunders Lumbar Traction Unit**, which helps relieve the aches from a hip replacement.
- **Orthopedic seat cushion**, for any activity that requires prolonged sitting. Hood attached a half cylindrical pillow to place behind her back.
- **Glucosamine with MSM**.
- **A Neck Wrap** designed to help relieve neck and shoulder tension, as well as keep the neck immobile. Hood uses it when her neck is aching, when she is making a craft and has to have her head down, or in a theater setting.
- **Physical therapy**.
- **Moist heating pads** that offer 12 to 24 hours of warmth.
Hood notes that alternative therapies alone aren’t meant to be a cure for someone with chronic pain. But she has learned that used in combination with medications, vitamins, supplements, exercise, and a healthy diet, people with pain can still have a quality lifestyle—something she has routinely advocated over the last 12 years with the ACPA support groups she has facilitated in the Danville area.

Learning to Live Again

“My quality of life is the best it has been in the last several years,” Hood said. “One of the things I stress to the group is getting out of the house. That could mean going to the library, or to a Starbucks to have coffee and people watch, or meet a friend. Or I encourage them to go to a nursing home to spend half an hour with one of the patients. Reaching out to others is very important to improving the quality of our own lives.”

Although Hood’s pain limits activities she used to love, such as gardening, she has found other ways to stay happily busy. She's decluttering various areas of her house, working on crafts, reading more, and entertaining friends for lunch and dinner. She enjoys quality time with her husband Bobby, a supportive force in life; her son Lorne, his wife Rose and their two daughters; as well as her daughter Barb, who lives in Berlin, Germany. And she knows that if her pain starts to interfere with her cherished activities, all she has to do is slow down and revisit her pain relief arsenal.

“When my pain started with that fall at camp, I wondered if I’d ever be able to do the things I love,” Hood said. “I am blessed by God to have a positive, tenacious spirit. His spirit has helped me cope each day. He has brought some wonderful people into my life to help and love onto me. I could never do this alone.”

To learn more about the CAM therapies mentioned in this article, visit these websites:

* [http://www.upledger.com/content.asp?id=61](http://www.upledger.com/content.asp?id=61)
* [http://pain.about.com/od/treatment/p/tens.htm](http://pain.about.com/od/treatment/p/tens.htm)

Young People Connect, Share Feelings on GrowingPains.org

To ease the minds of concerned parents, a “Community Manager” moderates the public content of the site. I am honored to take on this role and hope to not only moderate, but also to help stimulate activity. Social networking sites are different from other websites in that ideally the users themselves generate the majority of the content, though they can also keep their journal entries private. In this sense, I see the role of the Community Manager as someone who nurtures the development of the community. I hope to spur discussion and facilitate connections between users, fulfilling my original vision for Growing Pains.

What Will These Users Discuss?

One of the GrowingPains.org community members recently wrote this as part of a public journal entry: “Why? I ask myself that question every day. Like why can’t I stop the pain? Why can’t I see any results? Why do I feel like it’s my fault? I’m in so much pain why don’t my family or my friends understand me?”

There are so many people living with pain who ask themselves the same questions. When you’re alone, it can seem impossible to move through the suffering, to stop asking “why?” and start asking other questions. Questions like:

* How can I be well even when I have pain?
* How can I communicate my needs to my family, friends, and healthcare providers?
* Where can I find a community that understands me?
* How can I better advocate for myself at school or work?

Eventually, through finding answers to these questions, people with pain can begin to acknowledge their own resilience, new skills, and relationships, and a deeper sense of purpose that might not have surfaced if it weren’t for their pain.

GrowingPains.org is a place where we can help each other on the journey from patient to person. If you are in need, or if you feel you can help, please join our community at [www.growingpains.org](http://www.growingpains.org)
Gentle Exercise of Any Type Brings Relief from Pain

by Loretta O’Donnell

One of the best things you can do for yourself—particularly when you are feeling poorly—is to take a walk or engage in gentle physical activity. Studies have shown that moderate exercise has many benefits besides building strength, and stamina, including releasing endorphins that will affect your mood.

When you are sick, sore, or aching, you may first think of taking a nap rather than exercising, but activity will have a more positive effect, because it improves your energy, stabilizes blood sugar, enhances your immune system, and often can reduce pain.

As a cancer patient going through chemotherapy for the past three years, I know that people who have undergone surgery, chemo, radiation, or treatment for other illnesses are often intimidated by the idea of an exercise program. They delay exercising because they are unsure of their abilities and limitations due to pain or side effects.

Pain, a symptom of many medical conditions that ranges from acute to chronic, can originate from nerves, bones, muscles, and organs. It can be psychogenic from emotional or mental stress. Regardless of the source, pain can significantly affect your ability to function and interfere with your quality of life.

Physical Therapy to Restore Function

For arthritis and musculoskeletal pain, physical therapy is often recommended to promote healing and restore function and movement. Physical therapists can help patients exercise safely as soon as they are cleared by their doctors to do so. The therapists will conduct assessments and monitor the client’s changing abilities, adding exercises, aerobics, and weights as appropriate.

Physical therapy can help relieve and manage pain through a combination of passive and active techniques. These may include stretching and strengthening exercises, postural education, and light to moderate aerobic activity. Strengthening abdominal muscles can help relieve lower back pain. Strengthening neck and shoulders can relieve upper back pain by improving posture. Exercise tools may include elastic bands, physio balls, and recumbent bikes to support the back. Weight-bearing exercises also help to preserve bone density and prevent osteoporosis.

Aquatic therapy can be particularly useful, reducing the stress on the body by minimizing the effect of gravity. Often, warm pool therapy is a viable option when pain from fibromyalgia or joints limits an individual’s tolerance to exercise on land.

Yoga and other gentle exercises are also more fun and invigorating outdoors.

More passive treatments incorporate moist heat/ice packs, ultrasound, electrical stimulation (TENS), and joint/soft tissue mobilization to manage pain. In general, ice is used for acute pain to decrease inflammation. Heat is used for sub-acute pain to promote relaxation, improve circulation, and facilitate tissue healing. For chronic pain, a combination of ice and heat is often helpful.

A Personal Experience

I was aware of the benefits of exercise from my daughter Laura, who is a physical therapist in Maryland. Laura and her doctoral degree team researched how yoga helped women undergoing chemotherapy for breast cancer manage the side effects of treatment.

So I asked my physician for a referral when I started chemo in 2010 and went to a physical therapy program near my home in New Jersey.

My therapists helped me to have less pain, better flexibility, and improve strength, endurance, and mood.

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Many Benefits for Cancer Survivors

Paul Vidal, owner of Specialized Physical Therapy in Cherry Hill, NJ, explained how many alterations or toxicities can affect the physiology and body functions during and after cancer treatment.

* Multiple body systems and organs can be involved.
* Cardiovascular changes make cancer-related fatigue a problem.
* Changes to the pulmonary system can make breathing difficult because of shortness of breath and low lung capacity.
* Abdominal pain may be experienced as a result of gastrointestinal irritation.
* Individuals may be thin and weak as a result of decreased absorption capacity of the intestines and changes in muscle fiber and bones, and may lose range of motion.
* The nervous system is affected by cancer treatment, as well as the liver and kidneys, so an individual may experience pain, swelling of the limbs (lymphedema), and dehydration.

“Given all these body changes that can occur, it is no wonder why individuals with cancer may also have difficulty with sleeping, body image problems, depression, and anxiety. The good news is that there is plenty of research that supports and promotes the role of exercise during and after cancer treatment,” Vidal said.

Carol Stratton, Director of Rehabilitation Services at Cooper University Hospital’s Bone and Joint Institute in Voorhees, NJ, notes that physical therapy for post-op patients can often start about three weeks after surgery. “It’s important to start moving as soon as safely possible because tissue can get tight and it only take about three days for muscle atrophy to start,” she said.

Exploring Yoga

I also go to the yoga and free exercise classes offered by my medical center, library, and YMCA.

The slow, deep breathing of yoga soothes and relaxes the body and mind. Yoga has been practiced for millennia because the gentle moves tone muscles, improve flexibility and balance, enhance circulation, build strength, and increase stamina.

I have practiced hatha yoga, one of the most common types, and meditation yoga. My yoga teacher finishes the class with a dancing and laughing exercise that leaves us feeling young and free. Both types leave me with reduced stress and a feeling of peaceful calm.

Walk, Run, and Move

I suggest you investigate classes at your local YMCA or YWCA, which may be offered at no charge for members or non-members. These small classes are similar to having a personal trainer for individual monitoring.

If you have trouble motivating yourself to exercise at home, it may help to use videos or games such as Wii interactive sports.

Walking is a great place to start and one of the best exercises people can do almost anywhere to feel better physically and mentally. You can also consider joining a mall walking group, which are popular because they are free and can be done rain or shine, heat wave, or frost.

Walking has the added benefit of getting out in nature, or socializing with others, which can provide a distraction from the pain and an emotional boost.

Summer is ideal for enjoying the fresh air and energy of the outdoors while getting in some daily exercise. I like to take my dog on long walks, as he encourages me to walk faster and notice more, to get out of my head and enjoy the moment. I also meet other dog owners and feel connected. Yoga and other gentle exercises are also more fun and invigorating outdoors. Try whatever works for you to get inspired and motivated; there are no rules. Just take that first step and you’re on your way to feeling better.

Loretta O’Donnell is a former journalist, who also worked as a press officer for the State of New Jersey and Burlington County. Now retired and on cancer treatment, she enjoys writing about her personal experiences as a way to help others.
It took a heavy blizzard to keep the members of the ACPA support group in Arlington, Massachusetts, from its regular monthly meeting last March. But meetings resumed in April, right on schedule, as they gathered to celebrate the group’s 13th anniversary. It is led by Cindy Steinberg, facilitator.

“I try to keep meetings fresh and relevant with a variety of guest speakers and formats,” said Steinberg. “We have a long-standing committee that meets to research and present specific topics. We also vary the format between large group discussions, small group discussions, and open topic meetings.”

Steinberg also serves as Policy Council Chair for the Massachusetts Pain Initiative and is New England Regional Director for the American Chronic Pain Association.

“We have a solid core group of members that attend almost every meeting throughout the year, some of whom have been coming all 13 years,” she said. During meetings, long-time members and brand new members will meet, mingle, and continue to attend regularly. The group is publicized through fliers in health care facilities and by health care practitioner recommendations, received because of their good reputation.

“Our members are so warm, welcoming, and supportive of one another. When a new person comes, everyone gives them a chance to speak a lot. They empathize with how difficult life can be with pain when you lack the kind of support and understanding we provide,” she said.

According to Steinberg, the members genuinely care about each other and are concerned when a long-time member doesn’t attend. They send cards and make monthly reminder calls as a way to check on other members. Eager to help, they often volunteer to make calls, update various chapter lists, plan programming, bake snacks, and work in the support group’s informational booth at community fairs.

Janice Dallas, a support group member, commented about the commonalities in the group. “Each and every member has a different story to tell, but we are all linked together by living with chronic pain. We understand just what is happening to each other in our common search for ways to cope with this disease,” she said. “That gives us a strong bond and keeps the group going, with a lot of help from Cindy and her ‘lieutenants’ on the organizing end.”

Member Ellen Robertson shared these thoughts: “We are all in the same boat, being in chronic pain, unlike others in our lives. Therefore we can openly share our thoughts, feelings, and resources. Though we might not like everyone, we care about, support, and—because of our leader’s loving manner—love each other,” she said.

Robertson said the longevity of the group is due largely to Cindy, “of whom we are very proud.”

“I think we provide a safe, comfortable place to share honest concerns, the worries and burdens of living with pain as well as the silver linings of our lives with chronic pain,” Steinberg said.
ACPA Updates

New on the Website: The ProActive Communication Kit for Healthcare Providers

The ACPA’s ProActive Communication Kit (PACK) is an educational tool for healthcare providers. This video is available through the Maze of Pain or at www.theacpa.org/proactive-communication-kit.

“Through this new video, the ACPA wants to familiarize healthcare providers with the free online communications tools that the ACPA offers,” said Penney Cowan, executive director of the ACPA. “These tools are easy to understand, and can do so much to help people with pain and their healthcare providers communicate more effectively and productively.”

In the video, Cowan explains that, “Chronic pain is what takes an active functioning person and changes them into a patient who is looking to their healthcare providers to fix them, so that they can come back to their everyday life. The ACPA tries to take that passive patient and make them an active participant in the treatment team so that they can become a person again.”

Health care providers need to know that pain management isn’t as simple as asking about the intensity of pain. Instead, ACPA suggests they look at the effect of pain on the whole person, through several easy-to-use tools that can be brought to a healthcare visit and kept with medical records.

- Preparing for your Health Care Visit—Allows people to track how pain has affected their mood, appetite, activities, sleep, and more since the last visit.
- Med Card—Allows people to keep track of all their medications, on a card that fits in their wallet.
- Quality of Life Scale—Rather than measuring one’s level of pain, this tool measures the ability of the person with pain to function.
- Fibro Log and Pain Log—Easy, graphic ways to identify pain triggers, the quality of life, function, sleep, fatigue levels, and more.
- Diabetic Peripheral Neuropathy—On a picture of a person, users indicate where their pain is, how it feels, and the intensity. This tool creates a visual record that can be printed and shared with their health care provider.
- Follow-up Sheet—Images remind people of instructions about medication, follow-up tests, treatments, appointments, dietary restrictions, and recommendations.

“Chronic pain is a complex formula of a number of different elements, and the person with pain has to be a part of the treatment team to begin the journey from patient back to person and live a full life,” concludes Cowan.

PACK is supported by an educational grant from TEVA Pharmaceuticals.

Termination of the Physician-Patient Relationship

Periodically, the ACPA hears from people with pain who have been “dismissed” as patients, dropped by their doctors for insurance issues or other reasons. Sometimes they are on medications that require careful monitoring or a gradual withdrawal. When a physician-patient relationship ends, and treatment is stopped suddenly, people may be left without professional guidance for managing their pain.

While we understand that there are two sides of every story, abruptly dismissing patients rather than facilitating a transfer goes against medical ethics and in some cases, licensing board guidelines.

Tom Wagner of the American Medical Association (AMA) Ethics Group works with the AMA’s Code of Medical Ethics.

According to Wagner, “the AMA and its Code of Medical Ethics have always maintained that physicians should practice medicine with a compassionate and caring manner toward their patients. The Code offers the following ethics opinion (policy) regarding the termination of the physician-patient relationship to be used as a guideline:

E-8.115 Termination of the Physician-Patient Relationship

Physicians have an obligation to support continuity of care for their patients. While physicians have the option of withdrawing from a case, they cannot do so without giving notice to the patient, the relatives, or responsible friends sufficiently long in advance of withdrawal to permit another medical attendant to be secured. —(1, VI) Issued June 1996

Wagner advises people in this situation to contact a state medical licensing board to learn of the proper process for terminating care. A 30-day notification in writing is required in most states, as a state medical licensing board can confirm. A list of state medical licensing boards is available on the AMA website: www.ama-assn.org.
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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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 Jessie  
Wife of Steve Phillips  
From your friends in San Diego

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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