



CHRONICLE



Navigating the Highway to Help and Information

by Penney Cowan, Executive Director, ACPA

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At ACPA headquarters, we receive a lot of phone calls from people looking for help. Often, when I answer the phone, the person at the other end sounds desperate, as if they have been running through a maze of health care, turning in one direction then another, encountering dead ends and detours.

All this frustration, while also dealing daily with chronic pain.

We know that living with chronic pain is challenging. But we also know that there is more to chronic pain than the pain. At the ACPA, we understand the many challenges and obstacles that each person with pain faces.

We know that it has never been easy to navigate the medical system under the best of circumstances. When you throw long-term persistent pain into the mix, it can be downright impossible.

People with pain search for new doctors, new treatments, and new pain clinics. We also search for support groups, emotional balance, and answers to family issues.

But along with these, we also need to manage the “side-effects” of pain: money problems, employment issues, and legal rights. Everything from getting a handicapped sticker for the car when your “handicap” isn’t visible, to asking for FMLA leave from a job, to finding money to pay for procedures that insurance companies consider “experimental.”



A Guide to Getting Help

In this issue we are going to look at some of these challenges and try to help you navigate through the maze of pain to get the assistance you need.

Financial assistance is just one area. Gaining access to care is another issue that is becoming increasingly difficult. The REMS (risk evaluation and mitigation strategies) that the FDA is imposing on all opioids only increases the difficulty of getting appropriate pain treatment.

It is hard to sort through the tangled roads that make up medical practice these days. It seems as if the road to getting access to care and help is endless. But we hope to provide you with some basic, first-step resources that will get you started on your journey.

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Helping People Find Help

by Erin Kelly

Whether you are looking for a new doctor, have trouble paying for prescriptions, or just want to talk to someone who understands, you can likely find help through the ACPA. Bringing people together with the services they need is an important part of the ACPA mission, accomplished by the staff at the headquarters office in California, advisors and board members across the U.S., and peer support group leaders in your community.

Kat Deering, ACPA's outreach coordinator, works with ACPA group facilitators (volunteers who lead peer support groups all over the U.S.) and also fields phone calls to headquarters. She sees first-hand the types of resources people with pain are seeking. Although ACPA does not provide medical advice or financial help, Deering has a vast pool of other agencies and organizations that she can recommend.

"We get a lot of calls from people trying to find a doctor or pain program in their area," Deering said. "We refer them to professional groups like the **American Board of Pain Medicine** or the **American Academy of Pain Medicine**. We can even print out a list of doctors in their area who are members of these professional groups, but then the callers have to do their homework to choose among those by calling them and asking questions."

Insurance problems and prescription drug coverage are growing concerns, Deering says. "A lot of people with chronic pain lose their insurance coverage because they can't work," she pointed out. "Some of the resources we give them are the **Foundation for Healthcare Coverage Education**, which is a clearinghouse for finding subsidized insurance anywhere in the



In helping others, we help ourselves

United States; **Hill-Burton** information, about a federal program that provides reduced-cost care; and **Families USA**, a healthcare consumer advocacy group."

"We also can refer people to other self-help groups," Deering explained. She frequently connects people with groups for fibromyalgia, repetitive stress disorder, shingles, back pain, and neuropathy. She also has contact information for caregiver and family member groups.

Although Deering uses a lot of online resources, she also has toll-free numbers for many organizations and even prints out Web information to mail to people who don't have Internet access.

When Facilitators Share

Deering says that a lot of her best resources come from group facilitators themselves sharing what they've learned. "One facilitator sent us a whole book he'd put together. It was an A to Z guide to chronic pain resources," she said. "They really help us keep up with what's useful."

Deborah Sampson-Johannes is an ACPA group facilitator in Richmond, California, northeast of San Francisco. She's familiar with the type of help new people usually ask for.

"Some people are referred to our group after they call the ACPA," Sampson-Johannes said, "and they tend to have a good idea of what we can do for them. But other people call because they saw my poster in the YMCA, and they usually don't know what resources are available to them. They often don't even recognize that what they have is chronic pain."

Sampson-Johannes has a standard kit of handouts she gives new group members. In addition to a group member application form and list of "do's and don'ts" for the group, she gives out the About the ACPA brochure, the ACPA **Quality of Life Scale**, a handout about choosing a pain management program, and a list of patient's rights that helps explain how to be an intelligent consumer of health care.

Among the resources she gives out, Sampson-Johannes says the **Quality of Life Scale** is one of her favorites because it helps people change their mindset about living with pain. "It's an alternate way of assessing how you're doing," she explained. "It's different from the 10-point pain scale doctors tend to use, which just describes how intense your pain is.

Information is no substitute for a kind ear

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The ACPA scale shows what state you are in and what you are able to do. It takes the focus off your pain and puts the focus on your life.” (You can download the Quality of Life Scale, which measures ability to function, at www.theacpa.org/people/quality_of_life.asp.)

A Primary Need: Understanding

But information is no substitute for a kind ear. Sampson-Johannes says that the primary resource many people need is understanding. “We do a lot of ‘consciousness-raising’ about chronic pain,” she said.

Sampson-Johannes helps people deal with the common side effects of pain that can be confusing and troubling: hopelessness and clinical depression, strained family relationships, worries about addiction, and money-related stress. “People need validation,” Sampson-Johannes explained. “They need to know they’re not the only ones with these problems, they’re not crazy, and they’re not necessarily drug addicts just because they use opioids.” Many ACPA group facilitators make themselves available to people who just need to talk. “I welcome contact,” Sampson-Johannes said, joking: “Maybe I should have become a therapist.”

She hasn’t had trouble with anyone taking advantage of her willingness to share her time, but she knows there are ways to set limits. “If someone was taking too much of my energy, I’d have to explain that he or she needed more than I can give. I would recommend finding a psychotherapist or additional support groups that could help with the other issues.”

Financial Concerns Hit Home

When it comes to financial issues, Sampson-Johannes considers herself

fortunate—she’s always had health insurance and mostly maintained a middle-class lifestyle throughout her struggle with chronic sciatic pain. But she knows others who faced drastic lifestyle changes when they became unable to work.

Sampson-Johannes worries about the people who are unable to find and take advantage of the programs available. She’s heard stories from concerned relatives about people who need help with a pain problem but are too mentally ill to agree to join assistance programs that could give them proper housing and medical care.

“The people who come to ACPA groups are generally high functioning,” she said. “We’re just the tip of the iceberg. Some people who are really suffering are not getting help.” People who are severely disabled by pain or who are barely making ends meet might not have the energy to find resources that could help.

But financial help is available and Sampson-Johannes has seen its impact on the lives of people with chronic pain. She knows people who have found government assistance programs to fund pain management treatment, housing, and even help coordinating care.

“A social worker is a wonderful resource for people with chronic illness,” she said. “My insurance doesn’t cover that in my case, but many assistance programs do—especially for people with multiple health problems.” She even knows of a grant program that covers the expenses of keeping a pet, since taking care of an animal can have great therapeutic benefits. “But it’s a lot of work to find these programs and get the benefits,”

she said. “It takes a lot of expertise to live without money!”

Expanding Outreach

Sampson-Johannes hopes she can help more people find ways to live better with chronic pain. “If I’m able, I’d like to do more outreach work,” she said. “In the past I’ve left flyers in medical offices and I organized a presentation at a senior living center—it would be great if we could organize some groups at senior centers; I’m sure there is a need.” She also is interested in ways to serve people whose economic status is below the middle class.

Whether it’s help finding low-cost insurance or just a sympathetic listener, ACPA members and staff are committed to sharing what they know about living well with chronic pain.

This objective is so important, that it ranks as step ten of the Ten Steps from Patient to Person: reach out and share what you know. “A lot of group facilitators get started because they’re looking to help themselves, to find something productive they can do,” said Kat Deering, “And that’s very okay! In helping themselves, they also help others.”

Online Resources Referenced

American Board of Pain Medicine,
<http://www.abpm.org/>

American Academy of Pain Medicine,
<http://www.painmed.org>

Foundation for Healthcare Coverage Education, <http://www.coverageforall.org/>

Hill-Burton, <http://www.hrsa.gov/hillburton/default.htm>

Families USA –
<http://www.familiesusa.org/>

Keeping It All Together: Resources for Assistance

by Penney Cowan, Executive Director, ACPA and Alison Conte, Editor

Trying to work through the processes and policies of the health care system, insurance coverage, doctor's offices, and hospitals is part of daily life for many of us. But it can be even more difficult for people with chronic pain.

Not only do we have more occasions to interact with these organizations, we must operate through the haze and constraints of pain. To manage pain, it is essential to pace activities that can intensify pain and limit stress and frustration in our lives. But gaining access to the resources and assistance we need to solve our financial, legal, and medical problems can only increase stress and frustration—certainly not what the pain management program ordered.

Fortunately the ACPA has many helpful resources and connections available by phone and on the Web. There are also many organizations that serve those with a specific illness or condition. Since everyone's need is different, we will provide general directions here and encourage you to explore further.

The ACPA Web site also provides links to organizations with a broad interest in health issues, often with a unique ethnic, international, or cultural focus, as well as those that can help with money or legal problems. Professional organizations are also listed. Go to the Resource or Links sections of the site, or call us at 1-800-533-3231, or email your questions to ACPA@pacbell.net.

Also, on the ACPA Web site, www.theacpa.org, you can view the:

- * Consumer Guide to Pain Medication and Treatments video
- * News about storage and disposal of medications and opioids

* ACPA Forums for answers about medication dosage and drug expiration dates and other issues

Health and Financial Assistance

Health Assistance Partnership

www.healthassistancepartnership.org
shiphelp@hapnetwork.org
 202-737-6340

This organization serves consumer health assistance programs as well as other non-profit health care organizations that help patients solve problems with health care access and health insurance.

California Department of Managed Health Care

www.hmohelp.ca.gov
 1-888-466-2219

The Help Center explains your health care rights and how to use your health care benefits. They assess health plans to be sure they follow the law and address member complaints in a timely fashion.

The Center for Medicare Advocacy, Inc.

www.medicareadvocacy.org
 860-456-7790

The Center provides education, advocacy, and legal assistance to older people and people with disabilities seeking Medicare and other necessary health care.

Families USA

www.familiesusa.org
 202-628-3030
info@familiesusa.org

This organization has been dedicated to the achievement of high-quality, affordable healthcare for all Americans, at the national, state, and community levels for 25 years.

NeedyMeds

(no phone line)
www.needymeds.org

Helping people who cannot afford medicine or healthcare costs, NeedyMeds delivers information anonymously and free of charge.

Health and Medical Resources Military OneSource

www.militaryonesource.com
 1-800-342-9647

This is a free service for active-duty, Guard, and Reserve service members and their families that includes a health coach to advise on good health habits, relaxation, and exercise.

Health Finders

www.healthfinder.gov
healthfinder@nhic.org

Developed by the U.S. Department of Health and Human Services, this site provides access to legitimate Web sites from more than 1,500 health-related organizations.

Additional information on chronic pain can be found at Mayo Clinic, www.mayo.edu; the Cleveland Clinic, www.ccf.org; American Pain Society, www.ampainsoc.org; and National Institute of Health, www.nih.gov.

National Women's Health Resource

www.healthywomen.org
 1-877-986-9472

An independent health information source for women, NWHRC develops and distributes up-to-date and objective women's health information based on the latest advances in medical research and practice.

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Men's Health Network

www.menshealthnetwork.org
202-543-MHN-1(6461) ext. 101
info@menshealthnetwork.org

MHN strives to reach men and their families where they live, work, play, and pray with health prevention messages and tools, screening programs, educational materials, advocacy opportunities, and patient resources.

Finding a Doctor or Pain Program

If you are interested in finding out what pain programs are available in your area, contact all the local health care facilities and rehabilitation centers and ask if they have pain management programs. If they do, have information sent to you.

Once you have all the facts, review each program to determine which one will meet your needs. You can get a complete list of doctors who are board certified in pain medicine through the American Board of Pain

Medicine. (Go to www.abpm.org and click on Diplomats and then on your state.) Lists of pain programs can be found at the Commission on Accreditation of Rehabilitation Agencies, www.carf.org.

Find more advice about choosing rehabilitation centers on the ACPA Web site.

Legal and Insurance Assistance

The ACPA *Chronicle* has published several articles on legal and insurance issue. These include:

- * "The Legal Side of Pain" [The ACPA Chronicle](#), Spring 2007, page 5
- * "Navigating through the Insurance Maze" and "Help for Managing Your Health Care Plan" [The ACPA Chronicle](#), March 2009.

Pain and Policy Study Group

www.painpolicy.wisc.edu

This group has issued a Progress Report Card, which provides a letter grade for each state based on the quality of its policies (laws, regulations, guidelines) which influence pain management.

Pain and the Law

www.painandthelaw.org

Developed by the Center for Health Law Studies at Saint Louis University and the American Society of Law, Medicine and Ethics, this group is funded by a grant from The Mayday Fund.

Families and Caregivers

The National Center on Caregiving (NCC)

www.caregiver.org
1-800-445-8106
info@caregiver.org

The NCC is a central source of information on caregiving and long-term care issues for policy makers, service providers, media, funders, and family caregivers. | TOP |

What Have You Learned on Your Journey?

At ACPA we believe that people who live with chronic pain can be the greatest source of knowledge and inspiration for each other. So from time to time, we ask our readers to write about their experiences for a future issue. This time, we'd like to explore self-discovery.

During the journey from patient to person, we switch our focus from what we can't do, to what we can do. And then, we do it.

At some point, each of us must decide that we are more than a person with pain. Tell us how you took a fresh look at yourself, explored your talents and interests and determined what activities you could do that would be satisfying and useful to you and to others. We are looking for stories, between 500 and 800 words that address these ideas.

Please send your stories to *The Chronicle* Editor, c/o The ACPA, P.O. Box 850, Rocklin, CA 95677 or to ACPA@pacbell.net by Jan. 15, 2010.

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Reassessing Your Job Skills and Redefining Who You Are

by Ann R. Blaskovich

Though you don't want to let your pain define you, some days managing it does seem like a full-time job. Despite your pain management skills, you may not be able to return to work at the same intensity as before.

But it is important that you not let being a person with pain become your identity. This is the time to take another look at yourself, to explore your talents and interests and determine what activities you can do now that can be satisfying and useful to you and to others.

Pain management may have helped you regain control of your life. While you may feel like a whole person once again, you may also want to resume—at some level—the activities that had meaning for you prior to your pain.

Having a full or part-time job or doing volunteer work might add meaning and purpose to your life. This activity may give you increased endurance and ability, making you think about working more hours, or returning to your previous job. It may also be a time to consider a change in career that would be more meaningful.

Do You Need To Work?

Many people with chronic pain qualify for disability benefits. While such benefits may be helpful financially, you might feel better about yourself if you were to return to gainful employment. However, that is not always realistic. For some people, returning to work means having to give up disability benefits even if they cannot work enough hours to make ends meet financially. Struggling financially can increase stress and pain levels, making it impossible to cope.

Short of returning to work, there are many things that you could do that would make you feel productive and provide you with personal satisfaction.

Before starting to look for a job, spend some time thinking about what kind of work is appropriate for you. It may be a significant challenge to identify work that will stimulate you intellectually and emotionally and is both interesting and within your ability. A job that doesn't suit you can produce stress and can be counterproductive.

Assessing Your Skills

Before you start a job search, you need to know what you are searching for. If you don't know where you want to go, you won't know how to get there, and you won't be able to tell whether you have reached your goal.



The first thing you need to do is some introspective analysis of yourself and what you have done before. You need to determine what desires you have and what skills you possess. The objective is to determine:

- * What you like to do
- * What you do well
- * What you don't do well
- * What's really important to you
- * What skills, experiences, and abilities you have
- * What your limitations are

This self-assessment will enable you to formulate some goals and targets for your job search, whether it be for a full- or part-time job, self-employment, or volunteer work.

Your local United Way is an important community resource that should not be overlooked. It can provide you with a listing of all agencies that can help you acquire new skills and find a suitable job.

Finally, if you do not need the income, but have free time or need to work to feel useful, volunteers are needed in a variety of areas in your community. For information about volunteer work, you can contact libraries, schools, churches, mosques, or synagogues, and community programs. And don't forget that being an active member of an ACPA support group is a wonderful way to make a contribution to others and solidify your own progress at the same time.

Additional Resources

You'll find more about job search skills, self-assessment, identifying your skills, setting goals, and communicating your accomplishments in *Staying Well, Advanced Pain Management for ACPA Members*, Chapter 7.

Ms. Blaskovich was formerly a human resources consultant and past president of ARB Associates, in McKees Rocks, Pennsylvania.

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Drug Interactions: How to be Aware of the Dangers and Take Steps to Avoid Complications

by Rich Nagy and Keith Volk, Pharm D Candidates, Duquesne University, Pittsburgh, Pa.

One of the difficulties of medication therapy is that prescription medications can sometimes interact with each other, with over-the-counter (OTC) drugs, with certain foods, and certain disease states. Unfortunately, drug interactions are problems that the general consumer knows little about. These interactions cause a variety of effects. In some cases they can make your medication less effective. But other interactions can cause dangerous side effects.

The most common type of interaction is a prescription drug-to-drug interaction. There are many examples with interactions ranging from mild to severe. One example is an interaction between tramadol and selective serotonin reuptake inhibitors (SSRIs), a common drug class used to treat depression. This interaction can result in something called serotonin syndrome, which is characterized by increased incidence of sweating, fever, episodes of mania or elevated mood, and muscle stiffness.

Over-the-counter Medications

Other drug-to-drug interactions can occur between prescription drugs and common over-the-counter (OTC) products. Many people think taking OTC medications with their prescription drug is safe, but in some cases it can be harmful. One common case is when individuals take Tylenol™ OTC without realizing that Tylenol is already in their prescription pain medications. Tylenol (acetaminophen) is found in products like Vicodin™ and Percocet. If this is not understood, a person could unknowingly take too much daily acetaminophen, which can cause liver damage. The FDA has recently lowered the 4000 mg daily limit to 3500 mg, and this limit should not be exceeded unless directed by a doctor.

Even less understood are drug to food/beverage interactions. Something as simple as grapefruit juice will interact with many cholesterol-lowering medications. Some of the statin drugs taken in combination with grapefruit juice could result in severe muscle aches and pains. Also, many medications have drowsiness as a side effect, and this effect can be significantly increased by alcohol consumption.

Educate and Protect Yourself

To avoid the complications of drug interactions, take steps to educate and protect yourself. A solid recommendation is to always use the same pharmacy to fill your prescriptions. Each pharmacy runs a drug interaction check with each medication filled for you, but the interaction check only covers the drugs they know about, i.e. the ones you receive at that particular pharmacy. Here are some other smart precautions:

- * Discuss each new drug thoroughly with your doctor or pharmacist to make sure there are no interactions with any of your current medications or with any of your regular OTC drugs.
- * When buying OTC drugs at the pharmacy, ask the pharmacist to check that your selection will not interact with any medications you have been prescribed.
- * Educate yourself about the warnings of your own medicines.
- * List your current medications on a card and keep it in your wallet.



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- Note: Student articles have been reviewed by their professors for accuracy.

Do I Have to Go Back to the Doctor?

by Penney Cowan, Executive Director, ACPA

Excerpted from *Staying Well: Advanced Pain Management for ACPA Members – Chapter One*

At some point, even if you have been successfully coping with chronic pain, you may need to return to your doctor. If you start experiencing new symptoms or start feeling poorly despite your efforts, then you should see a doctor.

Making a return visit to the doctor can be very difficult if you have maintained a healthy profile over a long time. It is natural to experience a variety of thoughts as you reestablish yourself with a doctor. All the hard work you've done to regain control of life may seem in jeopardy when you're not feeling well. You may think that you are failing at pain management. Perhaps you had become overconfident and thought that pain would never control your life again.

But, here you are. You have been increasingly tired, sleeping poorly, unable to maintain a normal activity level, and feeling physically bad.

Many of the old stigmas common to people with chronic pain fill your thoughts. If you choose to see a doctor, will you be taken seriously? Will you be brushed off as a “chronic complainer?” Will you have to undergo numerous tests and try new drugs? Will your family support you or question the legitimacy of your pain? What will people think if you become “sick?”

You must remember that just because you conquered your chronic pain problem and have maintained a reasonable level of functioning, you are not indestructible. Our bodies can break, even when we are taking exceptionally good care of ourselves. It is important to be realistic about maintaining wellness realistically. That means you must listen to what your body is telling you. If you feel there have been significant changes in your health, you need to see a doctor.

Everyone Needs Doctors—A Personal Story

When you have maintained a healthy posture and applied pain management to your daily life, it is tempting to ignore new symptoms. I have done that myself.

Several years ago I was feeling tired, sleeping poorly, and unable to maintain my activity level. But I felt that because of my experience on a pain unit, my work with the ACPA, and my success at resuming my life, I didn't need to see a doctor for a check-up. I assumed that my new symptoms weren't



important. I also feared what would happen if I, the founder of the ACPA, got sick. I worried that people would question the value of the ACPA.

I forgot about listening to my body, accepting my limitations, and being realistic about regular check-ups. Plain and simple, I was afraid.

It was fear that prevented me from admitting that I wasn't doing as well as I would have liked. Old habits of putting my needs last, ignoring what my body was telling me, and not giving myself the benefit of the doubt returned. I assumed the worst, and my fear grew with each passing day.

After leaving the pain unit 10 years earlier, I wrongly thought that I no longer needed doctors. I did everything in my power to avoid them and to stay a well person. I was unrealistic and, frankly, not very perceptive. I ignored what I'd been teaching ACPA members for the past 10 years. Somehow, when it came to me, I thought the rules didn't apply.

It was the decrease in my activity level and lack of energy that prompted me to disregard the teachings of the ACPA and hide from the truth. But I was human, and as I became more and more fatigued, and as my pain level increased, I knew I needed help.

With a great deal of apprehension, I sought the help of a doctor. I felt broken and ashamed for just being in his office as a “patient.” The visit was not easy and I had a difficult time communicating. Fear was my controller: perhaps if I only told him half-truths, he would find no serious problems.

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An even greater fear was that after all the tests were done he would find no reason for my ill health and I would revert to being a patient again instead of a person.

Fortunately, my fears were unfounded. My problem was quickly diagnosed and successfully treated. If I had been more realistic and less stubborn, I could have saved myself a great deal of suffering.

Fearing Failure

Advanced pain management can be difficult for those of us who have maintained a “well person” role for any length of time. If we don’t feel well, we worry that we are failing at pain management. We forget that our bodies change and that change is quite normal and can be easily dealt with. Going from the role of a patient to that of a person is difficult. However, it is even more difficult to stay well informed and realistic about our health when we fear returning to the “patient” role.

Remember:

- * New symptoms do not necessarily mean that your pain problem has progressed.
- * “Flare ups” don’t mean that you’re failing at pain management.
- * Schedule a “well visit” for a routine check-up—something everyone should do, not just those of us with chronic pain.
- * Be sensible and realistic. You can be a “person” and see your doctor for regular check-ups, too. That is called prudence, not failure.

Visiting a doctor doesn’t mean that you are looking for something to be wrong or that you’ve failed at pain management. It means that you’re taking care of yourself.

Navigating the Highway to Help and Information

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If you have not visited the American Chronic Pain Association Web site (www.theacpa.org) lately, you might want to take some time over the next few weeks to explore all the educational materials that we have posted. They are readily at hand—day or night—to help you take an active role in moving from patient to person.

And if you don’t have access to the Internet, just call us at 1-800-533-3231. Someone who understands will answer the phone.

FOR MO McCABE, FOR ALWAYS
BEING THERE FOR ME.

Given by Nikki Gillies

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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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.

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To Feel Better, Change What You Eat

How Nutrition Can Decrease Chronic Inflammation and Help Manage Pain

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

When we look for relief from pain, it might be a good idea to turn away from the medicine cabinet and investigate the refrigerator instead. Proper nutrition can make a difference in the pain you experience, boost your energy level, and increase your tolerance for life's challenges.

Indeed, many nutritionists believe that a healthful diet can make a positive difference for someone experiencing chronic pain¹. Making incorrect food choices could trigger inflammatory reactions in the body, causing or increasing pain, zapping your energy levels, and putting daily goals out of reach.

Much has been written about eating for proper nutrition, and when I work with people with chronic pain and chronic disease they often question which fruits and vegetables have the least amount of pesticides and what types of oils and foods are helpful for decreasing inflammation and pain.

Avoid Saturated Fats and Lower Your Cholesterol

Most of us are familiar with the role that LDL—the bad cholesterol—plays in forming plaques that narrow the arteries and increase the risk of heart disease. HDL—the good cholesterol—picks up excess cholesterol, and takes it back to the liver that eliminates waste.

In *Spontaneous Healing*², Dr. Andrew Weil states that polyunsaturated oils (such as safflower, corn, sesame, sunflower, and soy oils) are known to be chemically unstable and can damage DNA, causing inflammation and degeneration. While the omega 6 fatty acids in sunflower and safflower oils reduce the risk of cardiovascular disease, they can also contribute to both allergies and inflammation.³

Butter, sesame oil, vegetable shortening, and margarine can also increase inflammation, so avoid foods that contain a high fat content, trans fats as well as saturated fats (found in coconut, palm and cottonseed oils, red meats, poultry, butter, and whole milk.) Since saturated fats are found in dairy products, choose low fat when buying milk, cottage cheese, and cheese.

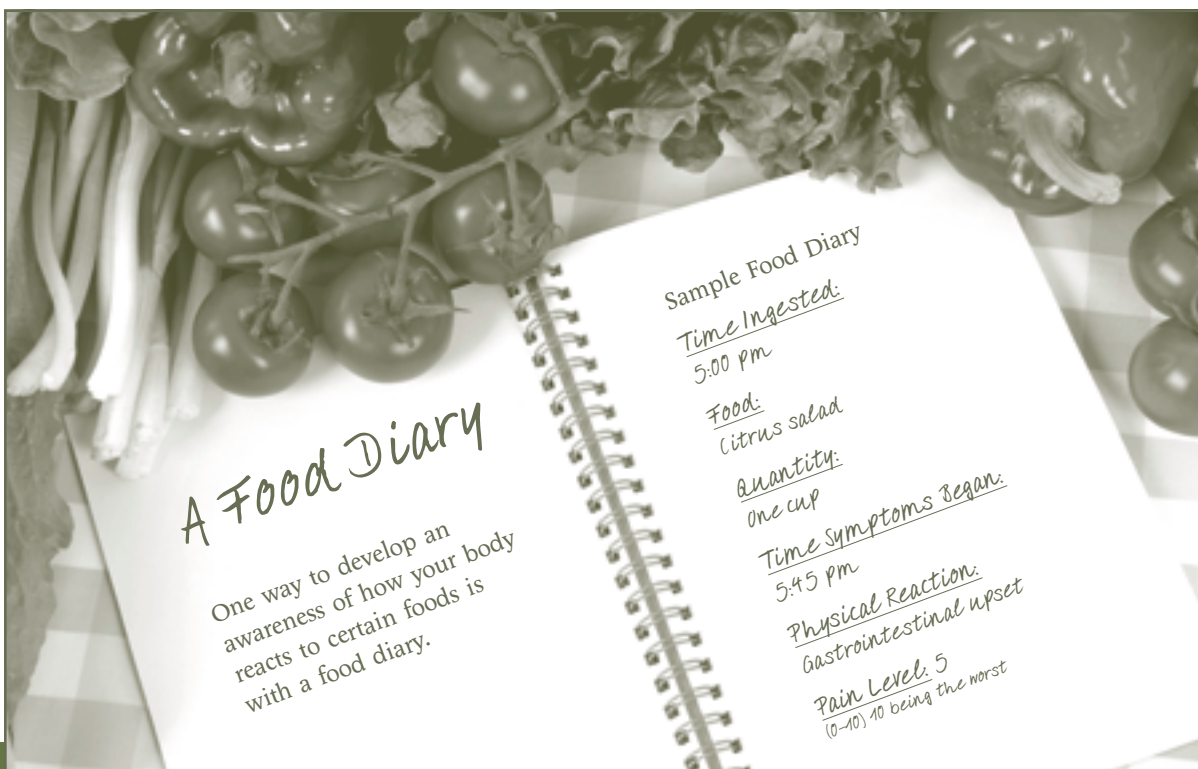
Peanut and canola vegetable oils, as well as olive oil, are mostly monounsaturated fats and are probably the healthiest oils to use in our diets.

Food Additives

Food additives need to be approached with extreme caution. For example, MSG (monosodium glutamate) can cause severe reactions in some individuals resulting in dizziness, headaches, nausea, and other problems.

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The Center for Science in the Public Interest⁴ identifies additives by level of safety, placing each into one of these categories:

1. Safe
2. Cut back (non-toxic, increased amounts may be unsafe)
3. Caution (may pose a risk, try to avoid)
4. Avoid (unsafe in amounts consumed or poorly tested)

Some people claim that the nightshade family of plants, like eggplant, tomatoes, and potatoes, can trigger pain in some people from a chemical alkaloid called solanine.⁵ Other foods said to exacerbate arthritis are nuts, coffee, dairy products, eggs, and wheat, as well as the previously mentioned foods. Though hard research does not exist, people with chronic pain may want to try eliminating these foods and then introducing them back into the diet one food at a time to judge the effects. Keeping a food diary can help you track your responses.

Beverages and Caffeine

Choose your beverages carefully. Sweetened “juice” drinks and sodas can deplete the body’s calcium, trigger carbohydrate urges, and increase insulin levels. Herbal teas, filtered or pure water, vegetable juices, and skim or low fat milk are better choices.

Limit your caffeine use as caffeine can interrupt sleep patterns and cause irritability, headaches, gastrointestinal upsets, and anxiety. Factors such as medication usage, anxiety issues, and hormonal issues all affect the way your body metabolizes caffeine.

Some medications either contain caffeine or interfere with the breakdown of caffeine in your body. Caffeine additives make pain relievers 40 percent more effective in treating headaches and help the body absorb headache medications more quickly, bringing faster relief, according to Web MD.⁶

This is why drugs like Excedrin, Midol, and many prescription drugs contain caffeine. But caffeine can also be harmful for a headache sufferer, causing withdrawal or rebound headaches.

Some antibiotics like Cipro can interfere with the way your body metabolizes caffeine, resulting in an increase in the length of time caffeine remains in the body, possibly exacerbating these effects. To control the amount of caffeine you absorb, carefully read the labels on the beverages and foods you are consuming.

Foods that May Trigger Inflammation

- * Bacon
- * Processed foods that are high in sugar and starch
- * Sausages
- * Full fat milk or non-dairy creamers
- * Chocolate
- * White bread or any item that contains wheat
- * Sugar
- * Dairy
- * Cream sauces
- * Hydrogenated margarines
- * High fructose corn syrup
- * Trans fats found in some crackers, cookies, cakes, fried foods, and margarines

Inflammation of the Nerves

Food choices can affect our pain responses and the inflammatory process. In his book, *The Chronic Pain Solution*, Dr. J.N. Dillard says that if our nervous system is devoid of fruits and vegetables, it might become unstable and send out pain messages. Foods like cake, cookies, sodas, and candy that are high in sugar content have been associated with chronic diseases and inflammation. Dr. Dillard also mentions that a deficiency in the B-complex vitamins has been implicated in pain caused by damaged or misfiring nerves.

Magnesium is responsible for both the contraction and the relaxation of muscles. A deficiency of this mineral could result in insomnia, anxiety, muscle twitching, and weakness. Although large amounts of magnesium can be ingested by eating dark green leafy vegetables, like spinach and chard, magnesium is also in bananas, nuts, brown rice, and beans.

In his book, *Foods That Fight Pain*, Dr. Neal Barnard tells us that inflammation can contribute to a myriad of health problems including, but not limited to, pain, headaches, digestive problems, psoriasis, and menstrual cramps. He indicates that two natural fats in plants act like anti-inflammatory medicines. The first is alpha-linolenic acid or ALA, which is found in fruits, vegetables, and beans, as well as flaxseed, fish, walnut, and canola oils. He states that the second fatty acid, gamma-linolenic acid or GLA, is rarer, but exists in evening primrose oil, hemp oil, borage oil, and black current oil. Dr. Barnard goes on to state that some medical centers have shown a reduction in pain, swelling, and stiffness with the intake of these oils.

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To Feel Better, Change What You Eat CONTINUED FROM PAGE 11...

To reduce inflammation in the body:

- * Stay away from fried foods and cook by broiling, grilling, roasting, or steaming foods.
- * Select from the entire color spectrum when choosing fruits and vegetables.
- * In between meals snack on fresh fruit and vegetables, as well as nuts and seeds (if you don't have allergies to them).
- * Avoid processed foods with large amounts of sugar and starch.
- * Read the ingredients on cereal boxes to avoid those that are loaded with sugar, have little nutritional value, and are low in fiber.



Choose Carefully

Remember to read the ingredients of the foods that you purchase. Avoid those that contain lots of sugar, but only small amounts of fiber, and have low nutritional values. Some foods that are popular for their anti-inflammatory benefits are omega-3 fatty acids, dietary fiber, salmon, pumpkin, walnuts, flax seeds, whole grains, and olive oil.

Nourishing your nervous system with healthy food and fat choices will provide your body with more strength and resilience to fight diseases and chronic pain, as well as decrease the amount of inflammation in your body.

(As with any change in your diet or pain self-management, please discuss your individual circumstances with your health care provider before starting on a nutritional program or beginning to take supplements. —Editor)

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- 3 http://en.wikipedia.org/wiki/Polyunsaturated_fat
- 4 The Center for Science in the Public Interest, www.cspinet.org/reports/chemcuisine.htm;
- 5 http://nutrition.about.com/od/dietsfor_medicaldisorders/a/antiinflamfood.htm
- 6 (www.webmd.com/migraines-headaches/guide/triggers-caffeine)

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- Barnard, N. *Foods That Fight Pain*, Three Rivers Press, 1998
- Dillard, J.N., *The Chronic Pain Solution, Your Personal Path to Pain Relief*, Bantam Dell, 2002.
- Environmental Working Group – <http://www.ewg.org/>
- Sandy Simmon's Connective Tissue Disorder Site – <http://www.ctds.info/magdiet.html>

Useful Web Sites and Books

- Zinckenko, D., Goulding, M. *Eat This Not That*, Rodale Inc. 2009
- <http://www.foodallergy.org/section/allergens>
- <http://www.mindfully.org/Food/Food-Additives-Avoid.htm>
- <http://www.healthyreader.com/2008/06/07/12-food-additives-to-avoid/>
- <http://www.nlm.nih.gov/medlineplus/ency/article/002423.htm>

ACPA Update

Welcome to our new groups and facilitators.

Christine Clark
Florence, AL

Cassandra Smith
Prescott Valley, AZ

Colleen Sanchez
Yucaipa, CA

Patsy Messer
Arma, KS

Tony Moffitt
Niles, MI

Adam Hensney
New York, NY

Patricia Hubert
Union/Essex, NJ

Joni Frazier
Christiansburg, VA

Fibromyalgia and More on the Web

In Fall 2009 ACPA launched "Understanding Fibromyalgia," a series of free educational presentations for people who live with chronic pain. Understanding Fibromyalgia (funded by Pfizer) is also on our Web site, along with a new tool called the "Fibro Log." It may help you better understand how different activities and circumstances may affect your pain and aid communications. You can find it through www.theacpa.org.

ACPA Annual Meeting

The ACPA Board of Directors met in Pittsburgh on October 10, 2009, and elected David Provenzano, M.D. as President. Dr. Provenzano is executive medical director of the Ohio Valley General Hospital Institute for Pain Diagnostics and Care, in McKees Rocks, Pa.

Nicole Kelly will stay on the executive committee as past president, with Dan Galia as treasurer, and Joanne Schneider as secretary. Penney Cowan remains executive director.

The board heard about ACPA tools that help support the needs of people with pain. These include:

- * Support groups in the U.S., Canada, the U.K., and other countries
- * Pain management manuals and publications
- * Consumer Guide to Pain Medication and Treatments and ACPA Coping Skills Calendar
- * Relaxation CDs and Pathways Through Pain videos

Newer tools help medical professionals and people with pain communicate using pictures and graphics that overcome language and literacy barriers. These include:

- * CARE Cards for understanding prescription instructions
- * Living Better with Pain Log to track pain triggers and progress
- * Quality of Life Scale to supplement typical pain scales by measuring function

- * Follow-up Sheet for remembering instructions from providers

In 2008-09, ACPA represented the voice of people with pain in legislative forums, in groups working on clinical practice guidelines and evidence-based medicine, and with national and state pain societies.

We enhanced our partnership with Kaiser Permanente members, who are now attending ACPA support groups and training as group facilitators.

We also held a regional directors' leadership conference in Chicago in September 2008 (funded by Medtronic Foundation). In May 2009 a Media and Advocacy Training for ACPA facilitators took place in Las Vegas, Nev. with support from Purdue Pharma.

Many new initiatives are available in print or [on the Web site](#):

- * Consumer guide to low back pain practice guidelines
- * Emergency Department Survey (to be published in *Pain Medicine*, funded by Cephalon)
- * Online five minute relaxation break
- * AgraAbility Project, "Growing Well with Pain" (funded by Medtronic Foundation)

In 2009 and 2010, the ACPA will continue to develop the [Consumer Guide to Pain Medications and Treatments](#), expand online forums, and translate more materials into other languages.

ACPA has plans to:

- * Promote the Pharmacist CARE Card on prescription bags
- * Partner with the Veteran's Administration pain programs to provide support groups for Iraq veterans and older veterans.
- * Collaborate with the Alliance of State Pain Initiatives
- * Redesign and add more interactive tools, videos, and forums to the Web site.



Board Member Profile: Andrew Bertagnolli

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

Andrew Bertagnolli, Ph.D. is the newest member of the ACPA board of directors, having joined in the summer of 2009.

Dr. Bertagnolli is a psychologist and is currently a senior consultant in behavioral medicine and pain management at the Care Management Institute of Kaiser Permanente in Oakland, California. He oversees the development of evidence-based clinical guidelines for managing chronic pain and key behavioral medicine issues like depression.

He also is the staff psychologist at Spinecare Medical Group in Daly City, California, where he conducts pre-surgical psychological evaluations.

In both roles he works with patients to help them manage their pain and deal with their emotional reaction to pain. "I have worked with people with pain for 20 years," he said. "It is somewhat unusual to have a psychologist as part of the team, either in spine surgical groups or in managed care organizations, but it is very helpful to the patients."

When people have spine surgery—often as an attempt to lessen chronic pain—Dr. Bertagnolli assesses their level of coping, before and after surgery. "While we tell them that surgery won't completely eliminate their pain, they often hope that it will. If the surgery is not as effective as they hoped, they can get depressed. I help them cope with that disappointment and manage the pain that remains," he said.

"I start the ball rolling, but ACPA is an extension of the work that I do," he said. He added that ACPA's strategy of making long-term behavioral changes to learn to live with pain can help balance emotional health as well.

"I have been involved with ACPA for a number of years, and met Penney [Cowan] at one of the professional pain meetings," he said. That relationship led to a better program for Kaiser's members who have chronic pain.

Now, many of Kaiser Permanente's Pain Programs incorporate ACPA's philosophy into their after-care plans. Members with pain are encouraged to attend ACPA support groups as part of the recommended discharge plan and Kaiser provides facilities in which to hold meetings. "Now there is no copayment each time. And our members see themselves as less of a patient and more independent," Dr. Bertagnolli said.

Dr. Bertagnolli received his bachelor of arts in psychology from Vanderbilt University in Nashville, Tennessee and his master's and doctorate degrees in clinical psychology from California School of Professional Psychology in Alameda, California.

Dr. Bertagnolli is also an adjunct professor at Alliant International University and the California Institute of Integral Studies, both in San Francisco. He has also been on the faculty of the Wright Institute, San Francisco State University, University

of California-Berkeley, and University of California-San Francisco. He serves as an expert reviewer for the California Board of Nursing and California Board of Psychology.

"We know that depression and anxiety can intensify pain," said Dr. Bertagnolli. "And functional MRIs show pain signals and emotional processes start in the same region of the brain. Because they are intertwined, it is essential to look at how pain affects emotions and how emotions affect pain if we are to successfully manage both."

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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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