How Important is Your Voice?

by Penney Cowan, Founder and Executive Director, ACPA

In healthcare this year, everyone is talking about patient centeredness and patient-centered care.

What exactly is patient centeredness? It is what all healthcare should be: putting the needs of the patient at the center of all treatments, tests, research, and development.

The big question is, are you at the center of your healthcare? Do you feel as if you have a voice every step of the way?

I can remember a time when I was a child that we could arrange for a “house call” if someone was sick. The doctor—often the only doctor in town—would actually come to your house. You and your family were at the center of your care.

These days, healthcare professionals (HCP) are stretched beyond belief, permitted only a short amount of time to spend with each patient.

A Movement to Shift the Focus
So how can we change the focus of care to what the patient needs?

You can no longer afford to be a passive patient who looks to a HCP to “make it better.” To become an active participant in your healthcare:

❋ Be prepared before your visit so that you can easily communicate your symptoms.
❋ Share pain management techniques you have tried, and whether or not they have worked.
❋ Be ready to list of all of your medications, over-the-counter drugs, and vitamins.
❋ Prepare a written list of questions.

The ACPA has a wealth of communication tools, many with graphics or interactive features, to help you track your health and activities in a simple, quick way. Some also work on your smart phone or tablet, so you can take the results to your appointments.

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At one time, most people seeing a doctor would simply accept the diagnosis, believing that the healthcare provider knew best. Today, health knowledge is more widespread, and individuals are able to research their conditions, ask questions, and be more involved in their care.

A patient-centered, patient-driven approach can lead to informed decisions, greater confidence, and ultimately, better care, as Cynthia Murphy and Tom Norris have found.

In the Beginning
In 1992, Cynthia Murphy, 56, of Andalusia, Alabama, was experiencing frequent migraine headaches. Her doctor conducted a tender point test, which measures the amount of pain a patient feels when pressure is applied at 18 points. She had pain at 11 of them.

Time passed and other pain conditions developed—degenerative disc disease, lupus, and more. Then Murphy was in a motorcycle accident with her husband Mike. Although she escaped with a broken arm, pain erupted years later. To help address the issues, Murphy sought out pain management doctors. She also underwent numerous surgeries, ranging from gastric bypass to orthoscopic procedures on her neck, knee, and back.

Despite everyone's best efforts, the pain was there to stay.

Experience was her Best Teacher
We've heard that “the apple doesn't fall far from the tree.” In Murphy's case, this applied to chronic pain. Her mother experienced many of the same conditions that Murphy now has. She remembered watching her mother struggle at doctors’ visits to recall what she felt, and where, on a particular day.

Having worked in the healthcare industry for 30 years, Murphy said she saw first-hand how important it was—for patients, their caregivers, and providers—to be self aware and communicate their needs. She worked closely with patients in hospitals and nursing homes as a dietary manager and nutritionist, documenting food histories, food allergies and diet instructions.

Murphy quickly realized that this approach would work well for her own life. She started managing her own patient history, compiling a list of surgeries, her doctors, allergies, diagnoses, medications, and more. Each time she visited a new doctor, she would hand over a copy of this file to accompany patient intake forms. Murphy was facilitating her own patient-centered care.

With Knowledge Comes Power
Murphy recalled one of her neurologists saying how important it was for patients to play an active role in their own healthcare.

“With chronic pain conditions such as lupus and fibromyalgia, many of the symptoms follow MS and other autoimmune diseases, so there's no one thing to test. It's just symptoms, so it's difficult to diagnose if patients aren't communicating about what they are feeling,” she said. “Keeping track of those symptoms—such as a headache or fatigue—and perhaps pain in a new place, is very important. You can be prepared to tell the doctor at your next appointment what has changed since the last one.

“When my doctors get my detailed pain history, and find that I'm well prepared for my visits, they tell me they wish every patient was like this. Even though they encourage their patients to be more self aware, they aren't. I realized very early on that doctors don't have time to sit there and hold our hands, so we have to be very specific about why we are there, and be prepared to ask questions,” she said.

Seeking Support Groups
With her pain management doctors’ encouragement, she became an ACPA facilitator for a group in her hometown. Her healthcare providers support her efforts by sharing information about Murphy's groups with their patients, and applaud her when she speaks to groups about chronic pain.

Attitude and Responsibilities
If attitude is half the battle when it comes to chronic pain, the other half might be honesty. Murphy said there have been many days that she has spent in bed. She tells Mike this means she's hurting, and bed rest is the only way to relieve that day's pain.
Everyone has a story to tell...and something to teach you.

Murphy sometimes has to keep her attitude in check because she doesn’t feel like a doctor is paying attention. For the most part, however, she's found a mutual level of respect with those who treat her conditions.

Pain care is a two-way street, Murphy said, and she reinforces this message with her support group.

“I try to encourage people to see past the mindset that ‘so and so is the doctor, and he/she should be asking me questions and telling me what’s wrong.’ It’s hard to change that old way of thinking. We need to be well educated when it comes to our bodies, and be able to communicate our conditions and our needs openly with our healthcare providers. Treating chronic pain effectively is a team effort.”

Accepting the Unexpected
Tom Norris, 66, of Los Angeles, had hoped to have a long career in the military. After nearly 18 years of serving in the Air Force, he was diagnosed unexpectedly with testicular cancer. A year after undergoing surgery and treatment at Walter Reed Medical Center, he began experiencing pain in his left hip. Not long after, his doctor found that the cancer radiation treatment had been too intense, resulting in internal damage to bones and connective tissue.

The pain soon intensified—to the point where he was judged “untreatable,” and was medically retired from the military. His only bright spot at the time was Marianne, whom he had just married. It was a very trying time, with Norris spending most of eight to 10 years in bed, attempting to cope with the pain. But with faith and the loving support of his wife, he said he was able to manage.

Coping as a Civilian
When Norris was in the military, he followed orders. But being forced to retire for health reasons threw him for a loop, and made him and Marianne second-guess this method.

“When I had to retire, I was told that I'd never be able to do anything because of the pain; that I'd never be good for anything, and that I would die from the radiation. My response was—hide and watch.”

“That's when I started realizing that I needed to be involved in my healthcare. I started going through the 'civilian playbook,' attempting to find someone who could actually help. My wife is an actress in Hollywood, so we connected with friends who suggested various types of therapies—magnets, queen bee honey, the Pneumatherm (deep heating)—anything to help us fight the pain. We weren't giving in, but instead decided that we would do everything we could to incorporate my pain into our lives and hold my advancing pain at bay.”

Becoming and Staying Well-Informed
Several years ago, Norris began having neck pain, a result of the spine issues that the radiation had initiated. The doctors told him he needed immediate surgery to fix his herniated disc. Norris disagreed.

Five opinions later, he found a doctor who agreed that surgery would not fix the problem. A year later, when the condition erupted on the other side of his neck, the doctor said the same thing.

Norris said he’s fortunate these days, as his trusted healthcare team allows him to “run the show.” He brings them questions and information he’s uncovered, and when he’s off base, Norris and the doctors discuss why.

When he visits his doctors, especially new ones, Norris carries complete records, as well as a summary of his pain conditions. Walking into the appointment without this documentation, he said, is like “walking onto a stage to perform and never having read the script.”

“One of the things I've learned is that you really have to love yourself and be willing to stand up for yourself when it comes to meeting with your doctors,” Norris said. “Doctors become doctors because they want to fix people, but with chronic pain, there is no fix. They can only help people who want to help themselves.

“So sometimes it takes going through several doctors to develop a relationship. Once you have that relationship, you can walk in there with your prime focus, showing what you have done, where you are now, what the problem is, and what you'd like to do. We, as humans, have that basic right—to stand up for ourselves and be in control. Doctors aren't gods and they aren't infallible.”
Having the Right Attitude is Key
During his childhood, Norris’ mother was a competent nurse, but dominated by her overbearing husband. As Norris watched this unfold, he began seeking positive forces—one of which was yoga. He began incorporating positive actions into his life, figuring out ways to direct his own future. At the same time, he watched his mother elevate her own standing in life to secure three degrees (bachelor’s, master’s, and a PhD), all while becoming “Madam Assertiveness.”

“My mom’s journey and the lessons she learned were the core of getting me where I am,” Norris said. “She stood up for her own rights, and those of others, whether they were her patients, other student nurses, or folks in our neighborhood.

“What I have taken away from this, as pertains to my chronic pain journey, is that we must believe that we are worthy of getting better, worthy of being healed, and most importantly, worthy of being treated like a human being. In my life, faith helped develop and maintain my attitude. You’re going to fall on bad days, but you learn how to get right back up. Every bit of life is learning.”

Supporting Caregivers
Norris credits his wife Marianne with a trait all caregivers are required to have—patience. Had she not come by this naturally, Norris said he would not have had carte blanche to “groan, scream, or spend days in bed to recover.”

When pain tests her husband’s limits, Marianne asks what she can do to help. When his answers are negative, she holds his hand and remains supportive.

Norris said although serving as a caregiver is a full-time job, caregivers shouldn’t give up their lives completely. Surrendering yourself, he said, is not a good idea, because caregivers still need to be themselves and love themselves. This is why he encourages Marianne to stay busy socially. If caregivers don’t take care of themselves, how can they be there for someone else?

Lessons Learned
Norris has been a member of the ACPA for about 20 years, and currently facilitates two groups in the North Hollywood area. He encourages laughter, belief in self, and listening to others.

“Everyone has a story to tell, and everyone you encounter has something to teach you,” Norris said. “And we individuals living with chronic pain also have to realize that we can teach ourselves—to speak up, to say no, to be informed and have the right to an opinion.

“We all have the ability to stand up for ourselves. We just need to be motivated to find that moxy.”

How Important is Your Voice?
Taking this active role means that you ask questions when you don’t understand why a course of treatment is suggested.

Here is why this is essential:

✱ You will be more likely to follow through with tests, exercise, or diet recommendations if you know why they are important.
✱ You must ask questions and get answers, because the fear of not knowing increases your worry and stress.

How well you will do depends on if you are ready to take action. As long as you are waiting for someone else to make you better, or for the next surgery or treatment to relieve your pain, your progress will be very slow, if you make any progress at all.

Cheer for Your Healthcare Team
We hear a lot about teamwork these days. Guess what? You are the captain of your healthcare team.

I think of the treatment team as a football team. Your doctor or other HCP is the coach. Other team players include nurses, physical therapists, counselors, family caregivers, and your pharmacist. But you must be the quarterback.

The team is there to support you and help you follow the plays that the coach calls (recommendations). If you sit on the bench waiting for your team to get to the goal, nothing will happen.

The center of all healthcare is you, the person with pain:

✱ You have a voice, you have needs, and you have questions.
✱ You must make your needs known and declare what you expect to gain from your treatments.
✱ You must follow through on the recommendations of your HCP.
✱ You have the ability to get out there and work as an integral part of the team.

Living a life with pain is not easy for most of us, but it is possible. The only way to travel down the pathway from patient to person is to be your best advocate. You can make a significant difference in your care.
Building Strong Healthcare Relationships

by Alison J. Conte, Editor, ACPA Chronicle

Patient centeredness may be the newest way to talk about a very old idea: you will get better care if you take the time to build a strong relationship with your doctor. Patient centeredness implies a personal relationship and mutual trust.

That’s what pain specialist Donna Kalauokalani, MD, MPH, believes. And to make this happen, she requires that the people with pain who consult her stay actively involved in their care.

“People with pain must want to engage, and be a part of their care treatment. That’s the only way it can work. I ask all my patients to be active participants,” she said.

She also requires that they have a primary care physician (PCP). “People who discredit the importance of having a PCP are missing out on preventive care, and the value of that relationship,” she said. “And I work to integrate my care with that of the PCP.”

Mutual Respect is the Foundation

According to Kalauokalani, what we are now calling patient centeredness evolved from the age-old need for good doctor-patient relationships. She says that people must know, respect, and trust their physician before they can truly value his or her recommendations. This mutual respect is what allows patient-centered care to flourish, she explained. Conversely, when a doctor knows a patient really well, it facilitates making recommendations that are truly in their best interest.

There are no short cuts to building a strong relationship; it just takes time. As Kalauokalani said, “When a doctor has taken care of someone for 20 years, there is less mystery in trying to understand what this patient needs.”

“You have to have trust in the person who is making the recommendation. The more you trust them, the more likely you are to follow through with a plan for care,” she said. “Today, care can be fragmented unless doctors and patients make the investment to build the high quality relationship they need,” she said.

Doctors and Patients Must Work Together

To facilitate communications, Kalauokalani encourages her patients to use the ACPA Pain Log. They use it online to track their pain, activities, habits, medication, sleep, and mood, and bring a printout of the results to their appointments. “That is part of my routine with my patients. Some embrace it more readily that others,” she said. “It is now also available as a convenient phone app.”

She points out that medical school teaches a lot about how to diagnose and treat illnesses in the clinical realm, but that some doctors come out of training with no idea how to talk to people about life-threatening or chronic, debilitating illnesses.

“This is a skill set. It takes effort to identify the need and the time to build that skill,” she said. “This is particularly true in chronic pain treatment, because pain is subjective and successful treatment is related to improving function and reducing suffering. Working to attain that depends on fostering a mutual understanding of what that means to the individual.”

“Having ongoing feedback has always been valuable in pain care,” said Kalauokalani. As she explained it, the quality of the clinical relationship affects the quality of the care. Patients want to be comfortable with their physician, build trust, and believe that they will get the help they need from someone who understands those needs and perhaps has helped to define them.

Donna Kalauokalani practices at Folsom Pain Management in Folsom, California. She serves as Medical Director for Pain Management Services at Mercy San Juan Medical Center in Sacramento, California. Dr. Kalauokalani lectures regionally and nationally about pain medicine and is on the board of directors of the ACPA.
When Patients Become Researchers

There's nothing new about patients being involved in clinical trials. Many believe the origins date to biblical times when King Nebuchadnezzar compared the health of soldiers eating meat to those who preferred legumes (such as peas or beans).

The first clinical trial to be published didn’t take place until the 1940s when researchers compared a group of tuberculosis patients that received the antibiotic streptomycin, to another group that received the standard treatment of bed rest.

Today, clinical trials involve more rigor and safeguards than they did 75 years ago, but one thing has remained fairly consistent: the trials are usually designed, overseen, and implemented by professional researchers and clinicians.

Expanding Study Teams

Patients have been consulted, but for the most part, they have been participants in studies, not part of study teams, says Lynn DeBar, PhD, a psychologist and researcher at the Kaiser Permanente Center for Health Research in Portland, Oregon.

“We haven’t always taken into account the patient’s perspective, but that is changing. Since our research is aimed at helping patients, it’s absolutely essential that we involve them every step of the way,” says Dr. DeBar. She is one of a new crop of researchers learning how to include people who have been patients as equal partners on the research team.

“It’s not easy. There is a learning curve. Because most patients are not trained in research, the process often moves more slowly, but it’s worth it because the outcomes are more useful to patients,” she said.

A Patient-Driven Process

Dr. DeBar’s most recent patient-centered study was “The Effects of a Patient-Driven Assessment Process with Complex Pain Patients,” or PDAP. The aim of the study was to evaluate a questionnaire that allowed people with chronic pain to describe their symptoms and their ability to do certain activities. The researchers wanted to know if people who used the questionnaire to facilitate discussions with their doctors experienced a reduction in pain and an increase in function.

People with Pain Have Valuable Feedback

Maris Burton was a patient stakeholder in the PDAP study. The 68-year-old Burton has had chronic pain for nearly four decades since he hurt his back lifting a box at work. For three years, Burton attended study meetings, shared stories with other stakeholders, and provided feedback about the patient questionnaire.

“The original questionnaire asked patients to rate their symptoms and activity level using a number scale. But one person’s five might be another person’s eight, so we decided the number scale was too subjective,” said Burton.

Burton and the other patient stakeholders modified the original questionnaire, getting rid of the number scale and providing more space for users to describe their symptoms and their ability to do activities they enjoy. The new questionnaire also has space for people living with pain to describe what their lives would be like if that ability got better or worse.

“We didn’t expect the patients to come up with a whole new form, that wasn’t something we could have anticipated,” says Dr. DeBar. “But ultimately the new questionnaire is more patient-friendly and we think it will be more useful.”

Learning about Patients’ Lives as People

Dr. Charles Elder, a Kaiser Permanente physician and member of the research team, used the new questionnaire with his own patients. He says it was helpful in two ways. First, he got to know his patients better by learning about the activities they enjoy. Second, it helped him change the conversations he’s having with patients to include their lives as people.

“We need to focus on what’s most important to them. Maybe their pain has prevented them from gardening or riding a bike. Even if their pain improves, but they still can’t do the activities they love, then we haven’t made the progress we need to make,” says Dr. Elder.

Dr. DeBar’s study followed 100 patients for 10 months. It found that, when compared with a control group, those who used the new questionnaire with their doctors saw bigger improvements in functioning and sleep.

A video report, Involving Patients as Equal Partners in Research, is on the ACPA website.
Raising Awareness of Chronic Pain Research Through RELIEF

by Neil Andrews, Executive Editor of RELIEF

The Pain Research Forum, at painresearchforum.org, is a website for pain researchers studying the causes of chronic pain and how to best treat it. This organization has just launched a new website called RELIEF (http://relief.news).

RELIEF translates the latest pain research findings into clear and accessible language for people with chronic pain, their families, and others interested in chronic pain. The site provides summaries of new research studies, interviews with leading pain experts, feature articles, podcasts, and webinars.

The goal of RELIEF is to help spread the word about all of the pain research taking place in labs throughout the world. This will help people with pain stay current with the latest scientific findings and be able to discuss them with their care providers, becoming more active in their pain treatment.

Sharing Scientific Research into Pain
The site also hopes to share this knowledge with the general public, policymakers, journalists, research funders, and even healthcare providers. This will help raise awareness of chronic pain in society, rally support for more research, and spark a national conversation about how to move pain treatment and care forward.

Scientists are making good progress towards understanding the basic biological mechanisms that underlie chronic pain. They are also using that knowledge to develop new treatments. Here are some recent articles published on RELIEF that highlight these efforts.

- **Complementary Therapies for Chronic Pain: What Does the Research Say?** This feature article describes the latest research on yoga, manual treatments, mindfulness, and meditation as therapies for chronic pain.
- **How Pain Arises—and What Might Stop It.** This is an interview with Allan Basbaum, a pioneering pain researcher at the University of California, San Francisco. He describes how chronic pain operates at a molecular and cellular level, and how the emerging understanding of pain is leading to promising new avenues to develop effective treatments.
- **Interview with Judy Foreman, author of A Nation in Pain,** in which she discusses what she learned about pain research and pain care, as she wrote her popular book on the problem of chronic pain in America.

Visit RELIEF to learn more about the pain research that is advancing the field. To sign up for a digest of each month’s new content, and/or to receive alerts whenever a new article is published, please visit http://relief.news/home/newsletter/.
If you live with or care for someone with chronic pain, you may be all too familiar with osteoarthritis (OA). Joint pain, stiffness, swelling, loss of motion, and other quality of life issues can accompany this disease. What may be less clear is how these symptoms can be managed. The good news is that there are a number of resources that can help.

OA is the most common form of arthritis, affecting about 27 million people in the United States. This rate is on par with cardiovascular (heart) disease. In fact, many people who have heart disease, diabetes, obesity, and other chronic illnesses also have OA. Unfortunately, joint pain associated with OA, even severe pain, is often overlooked when other chronic conditions are discussed during doctor’s visits.

Why does this matter? Because the same tools—such as exercise and weight loss—can be used to manage more than one disease. When joints hurt, people are naturally less active. They struggle to manage their weight or improve their chronic disease symptoms. This vicious cycle is particularly difficult to stop when joint pain is left out of conversations with doctors.

A Blueprint for Action

Unfortunately, too few people with OA understand how they can improve their own wellbeing and slow the progress of this disease. Resources for education and access to evidence-based physical activity programs for OA have not been widely available, but this is beginning to change.

The Centers for Disease Control and Prevention (CDC), the Arthritis Foundation (AF), and 70 stakeholders developed A National Public Health Agenda for Osteoarthritis (2010). It provided the nation with a blueprint of recommendations for dealing with OA. These recommendations focused on teaching people how to manage their own disease using physical activity, weight management, and prevention of joint injury; as well as environmental and policy solutions, and key research priorities.

To translate this blueprint to action, the CDC and AF then mobilized the OA Action Alliance (OAAA), a coalition of public health leaders and interested organizations committed to elevating OA as a national health priority.

Uniting Organizations for Progress

Based at the Thurston Arthritis Research Center at the University of North Carolina since 2014, the OAAA has more than 70 member organizations and is growing. Its mission is to proactively minimize the individual and community impact of OA.

To date, the OAAA has made significant progress on several key fronts.

- Through its policy and advocacy group, the OAAA is educating members of Congress, including the Arthritis Caucus and appropriations committees, about the importance of arthritis-related research and programming.
- The OAAA awarded three small grants to community-based organizations to advance objectives outlined in the 2011 report, Environmental and Policy Strategies to Increase Physical Activity Among Adults with Arthritis and its accompanying online Implementation Guide.*
- Many member organizations, including the ACPA, are providing valuable resources. ACPA Executive Director Penney Cowan lends her unique insight and perspective as vice-chair of a working group that shares self-management strategies and resources with individuals with OA, their family, friends, and caregivers.
- The OAAA is working with The Obesity Society to educate healthcare providers on the impact of obesity on joint health.
- Each month, the OAAA’s “Lunch and Learn” series invites experts to give free, live webinars that are open to the public. Penney Cowan is scheduled to speak on June 15, 2016. Registration and archives are located on the OAAA website, at oaction.unc.edu/events.

Managing chronic pain and other symptoms associated with OA is a complex challenge that is best approached by leveraging the benefits of many educational and therapeutic strategies. This is why the OAAA has a broad base of strategic goals and implementation plans. Our dedicated volunteers and staff work passionately to help those who live with the burden of OA.

Author Kirsten Ambrose, MS, CCCP, is Program Manager of the OA Action Alliance at Thurston Arthritis Research Center, University of North Carolina. Learn more at oaction.unc.edu.

* Find the report at oaction.unc.edu/policy-solutions/ and the guide at oaction.unc.edu/implementation-guide/
Living Well – and Sleeping Well – With Pain
by Erin Kelly

ACPA Updates

ACPA Chronicle Available Online
The ACPA Chronicle will become an online-only newsletter starting in August 2016. This April 2016 issue will be the last to be printed and mailed.

* A new Chronicle will continue to be posted three times a year, during early April, August, and December at theacpa.org/Chronicle. It is free and available to everyone.

* The newsletter content can be searched by anyone using the ACPA website.

* We have archived more than 40 issues, going back to 2005, at theacpa.org/Chronicle-Archives.

We also send out an email notice when a new Chronicle is posted. If you do not currently get this notice, simply sign up at theacpa.org/stayUpdated.aspx.

If you currently get a printed version of the newsletter in the mail, wish to continue to read it, and do not have access to the Internet, contact:

Chronicle Subscription
The ACPA
PO Box 850
Rocklin, CA 95677
1-800-533-3231

New Communication Tools
The ACPA Pain Log and Opioid Induced Constipation Conversation Guide are now available as phone or tablet apps. You can download them through the Apple App Store or Google Play. These apps will allow you to track your symptoms, set reminders, view your progress, and share it all with your healthcare provider. Visit the ACPA website for details.

Another new tool is the Migraine Conversation Guide, (under Communication Tools or at theacpa.org/uploads/documents/ACPA_Migraine_Guide.pdf) It will let you track symptoms, mood changes, and possible triggers related to migraine headaches, helping you to have meaningful conversations with your doctor.

Our new video, Pathways Through Pain: Priorities and Goals shows how people with pain become actively involved in their recovery.

HELP
HOPE
LEARNING

ACPA Event in Austin
The ACPA will be in Austin, Texas, on May 11, 2016, to present “About Pain Management, a Help, Hope, and Learning Event,” along with the American Pain Society. The event, which is free and open to all, will be at the J.W. Marriott, 110 East Second Street, Austin, in rooms 310-311, from noon to 4 p.m. Refreshments will be served. Please call 800-533-3231 to make a reservation.

Penney Cowan Presents Webinar for OAAA
Each month, the Osteoarthritis Action Alliance (OAAA) offers “Lunch and Learn Webinars” featuring medical and pain experts. The webinars are free and open to the public. Penney Cowan, executive director of the ACPA, is scheduled to speak at noon (ET) on June 15, 2016. Registration and archives are located on the OAAA website, at oaaaction.unc.edu/events.

Know Your Online Pharmacy
Buying medicines online can save money, but it can also be risky. To help you identify legitimate online pharmacies, the FDA suggests you visit fda.gov and search for BeSafeRx—Know Your Online Pharmacy.

Fake online pharmacies use sophisticated marketing efforts or phony storefronts to appear legitimate. If you use them, you could buy products that may contain the wrong ingredients, or too little or too much of the active ingredient, or contain other harmful substances. This could mean that you experience side effects, don’t get the results you expect, or become ill. The FDA recommends that you use only online pharmacies licensed in the United States.

ACPA Facilitator Recognized
Sandy Rozelman, an ACPA support group facilitator in Ohio, has been recognized as a distinguished professional in her field through Women of Distinction magazine.

Rozelman, who lives with chronic pain due to Fibromyalgia, is an inspirational, humorist, and author. For more information, visit breakingthecycleofpain.com or youregonnalaugh.tateauthor.com.

Veterans In Pain Events
As our veterans return home, many with injuries and chronic pain, we need to help them to return to a full life. The ACPA Vets in Pain program does just this, through support and education.

Meetings focus on pain management, starting and maintaining peer-led support groups, and maintaining wellness. There is no charge, but guests must register for these meetings by calling 1-800-533-3231. Learn more at theacpa.org/eventListing.aspx.
Book Review

*How to Live Well with Chronic Pain and Illness*
written by Toni Bernhard

Review by Tara White, RN

Just when you think Toni Bernhard cannot possibly come up with another powerful self-help book, she does just that. Her wisdom continually bubbles to the surface like an irrepressible underground spring. Using real life scenarios, she deals with all the feelings, difficulties, and dilemmas we all encounter with integrity, compassion, and honesty. This book is not only for those in chronic pain or illness, but also their caregivers, loved ones, and maybe especially any non-believing relations.

Forced to give up a stellar career as a law professor, Bernhard has pursued a writing career from her bed using a laptop computer. In this, her third book, her down-to-earth writing style presents wonderful ideas about how to live well despite physical limitations.

As she states, “If there’s no escaping our measure of disappointment and sorrow, then the path to peace and well-being must lie in learning to open our hearts and minds to embrace whatever life is serving up at the moment. This is mindfulness practice—mindfulness infused with compassion for ourselves.”

Her wise use of equanimity, mindfulness, and compassion come from her many years of immersion in the Buddha’s teachings, not as a religion, but as a practical path for finding real peace in life as it is.

This can be extremely valuable when you are confronted by friends and family who either do not believe your pain or are unable to respond to it in appropriate ways. Such behavior is not to be taken personally, but rather, to be accepted without hurting anyone’s feelings or dignity.

She points out that allowing compassion for self and others to arise out of any suffering, is simply being as kind to yourself as you’d be to a loved one in need.

Those that follow Bernhard’s blog *Turning Straw into Gold*, will love to see her discussion about what to say and what not to say to those who are chronically ill.

Bernhard states that all we can do is try our best to evaluate our circumstances and our needs, and then choose the course of action that appears to be the most beneficial and compassionate for us. It’s not the fact that we don’t get our way that makes us miserable; it’s how we respond to that fact.

In light of this, Ms. Bernhard provides us with her own recipe for peace of mind: one dose stark reality (acknowledge and accept), one dose practical skills (cultivating compassion for ourselves and others), and one dose of humor (good medicine for the heart and mind). With this recipe, she suggests we “cook up” a place of peace even in the midst of our health struggles. What a lovely family heirloom recipe to pass down to subsequent generations!

Equally graceful and helpful are the Buddha’s teachings on skillful speech. In replying to other people or ourselves, we should speak only when what we have to say is true, kind, and helpful.

Once you begin to treat yourself with kindness, you can calmly and gently begin to examine the actual physical discomfort. A physical sensation of pain is not the solid block of discomfort we think it is. Rather, it is made up of multiple sensations that are constantly changing. Remember that your negative feelings are impermanent as well. They arose, and they will pass.

This book is so honest, so real, and so practical, it is a must have for everyone, patient and caregiver alike. I simply cannot recommend it highly enough.

Sprinkled throughout are beautiful quotes and reflections on kindness. I just love reading them over and over again, so I’ll end with this one.

“In tenderness and kindness are not signs of weakness and despair, but manifestations of strength and resolution.”

—Kahlil Gibran

Book Review

The Fabric of Health
written by John W. Cardano

Review by Tara White, RN

Here is a great little paperback that will be especially meaningful to veterans and those who care about them.

Seriously wounded by an explosion in Vietnam at age 22, John Cardano suffered severe nerve damage and pain. He had to overcome PTSD, as well as stage 3 bladder cancer later in life. His journey to rebuild his health has lasted 44 years and has become his life’s work.

The traditional pain medicine route, he says, not only masks the immediate issues without resolving them, it can lead to new problems that are equally serious, including depression and addiction.

Pain and suffering supplied the immediate motivation, yet he states that “ultimately it was my deep desire to live life to its fullest” that caused him to change his circumstances.

Once he was ready, he made a personal commitment to live with conscious awareness and to take responsibility for his own health. He discovered that the role we choose and the actions we take every day can still determine the quality of our life and help us overcome almost anything, even when we have been told there is “no hope.” He gave up his medications and cut back on drinking. He immersed himself in non-traditional ways of healing. Furthermore, he took trips to study a variety of holistic health practices.

Cardano says that he began to understand that there are four elements of being—body, mind, emotion, and spirit. Living, he determined, is a “fabric that is woven by us each day and that establishes the blueprint for how we will handle the events of tomorrow.”

“Harmony or disharmony of emotions generate vastly different experiences in our lives. Confusion, anger, impatience—oh, so many disharmonies can disrupt our potential.” Yet, he also stresses that behavioral options are always available and personal involvement in one’s health decisions are critical. This sets the stage for empowerment. This then helps to develop powerful, life enhancing attributes that can remain with us throughout life.

The author says that a veteran’s ability to perform beyond normal physical limits is drawn from “the human spirit, mental focus, and emotional power—all elements of the fabric of our being. It is these non-physical dimensions that can enable a traumatized soldier or a severely damaged body to keep moving forward to an intended goal.” The emotional dimensions proved more difficult to accept. With incredible insight, he realized that the more he identified with being a wounded person, the deeper he sank into forever being wounded. Instead, he found new, positive ways to engage himself.

He threw himself into the studies of acupressure, massage, reiki, and omega Shakti—the studies of focusing and enhancing life force—which enabled him to expand and develop his potential to channel energy in support of healing.

He also studied Taoism, Hinduism, Ayurveda (the Indian science of life), Native American spirituality, quantum physics, abdominal conscious breathing, and others; all of which deepened his insight into a deeper understanding of life and health.

He states that we are “spiritual beings involved in a physical adventure, with a mental ability and an emotional power system. The central challenge of the adventure is to evolve in a way that keeps the entire fabric in harmonious flow.” He also believes that “our bodies slowly become an expression of the consciousness we live. When decisions we make in our lives cause us tension, the disharmony that creates within our energy field ultimately manifests itself in our overall health… getting better means embracing a new quality of life with enhanced opportunities.”

This book and the alternative medicine modalities it presents are certainly worth a try. Learning to trust in our own resilient and flexible strength supports health on a personal level and for society as a whole.

GET TO KNOW YOUR OVER-THE-COUNTER (OTC) MEDICINES

Being aware of active ingredients, dosage, and how an OTC medicine might interact with other medicines and current health conditions can greatly reduce the risk of overdose or misuse for you and your loved ones.

1 in 3 think it’s OK to skim the drug facts label on OTC medicines

2 in 5 think OTC directions are just guidelines

WHO’S BEING SAFER?

Women

- 62% believe it’s very important to read the label on an OTC

- 81% think it’s very important to read the label on an OTC they’ve taken before

Millenials

- 54% read the label on an OTC they’ve taken before

- 82% think it’s very important to read the label on an OTC they’ve taken before

Minorities

Hispanics and African-Americans are more likely than Caucasians to find the active ingredients very important:

- African-Americans (72%)
- Hispanics (56%)
- Caucasians (58%)

READING THE LABEL

RX v OTC

- 76% say it is VERY important to read the drug facts label on an OTC medicine they haven’t used before

- BUT ONLY

- 41% say it is VERY important to read the drug facts label on an OTC medicine they’ve used in the past

- 84% say it is VERY important to read directions on a prescription medicine

- BUT ONLY

- 72% think that is true of OTC medicines

The consumer attitudes survey on OTC medication was conducted from July 13-20, 2015 with a total of 2,038 U.S. adult respondents.
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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 donations and purchase of materials keep the ACPA alive and reaching out to even more people with pain.

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Given by
Fremont, Nebraska Chapter of the ACPA
Mary E. Peters-Davis, Jennifer Barling,
Susan Clinkenbeard, Phyllis Kathol,
Virginia Livingston and Jim Redmon

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

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