



CHRONICLE



Transforming Pain Management

by Penney Cowan, Executive Director, ACPA

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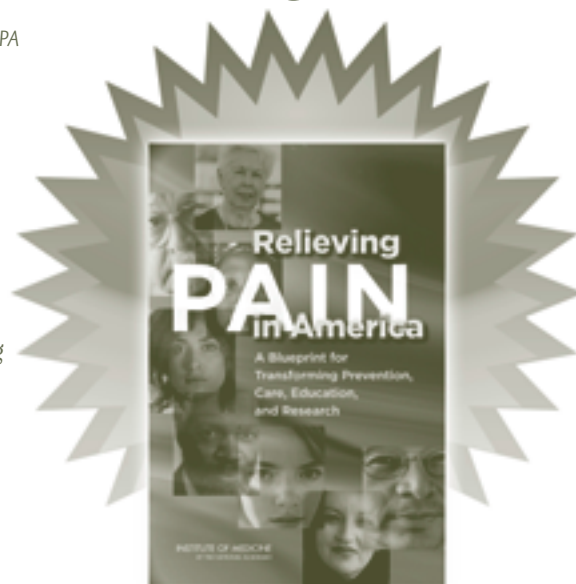


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Every once and a while a great piece of news comes along that can actually have a positive impact on our lives. That is certainly the case with the recently published Institute of Medicine Report: *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research* released June 29, 2011. The thing that struck me about this report—among the many positive things about this report—is that it validated what the American Chronic Pain Association has been doing for the past 31 years.

The statistic on how many people live with some form of chronic pain, 116 million Americans, confirms what John Bonica, M.D., the founding father of multidisciplinary pain management, said in *Time Magazine* in 1984. He said that about one out of every three people in the United States (2011 population of 312 million) is dealing with some form of chronic pain. The cost of pain is more than \$600 billion a year in health care and related expenses. That is more than diabetes, heart disease, and cancer combined.

What we cannot forget is that behind each of those numbers is a person. A person who has a life, a family, a job, and obligations. However, the need to deal with pain casts a shadow on that person's ability to plan for the future, and fulfill his or her obligations.



These numbers are impressive and alarming. These numbers should make us all stand up and take notice of the enormous problem of people living with pain. The numbers should generate a sense of responsibility among the health care community to become more knowledgeable about treating pain, and to help people manage it so that they can have their lives back. The numbers should encourage researchers to explore the mysteries of pain and discover the means to reduce suffering.

Education Needed for Everyone

The report pointed out the need for education by all health care providers no matter what their specialty. This is key because pain cuts across all areas of medicine including research. We cannot forget that the person with pain, their family members, employer, health care insurer, and the person on the street must all be educated in the multifaceted issues of pain.

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New Report Examines Relieving Pain in America

by Alison Conte, Editor, The Chronicle

Pain is—far too often—why so many of us go to the doctor, take medicine daily, remain on disability and live with limited activity and productivity. Given the burden of pain in human lives, dollars, and social consequences, shouldn't relieving pain be a national priority?

This epidemic of chronic pain in the U.S. is well known to those associated with the ACPA. But now, finally, it is getting national attention in government circles.

The 2010 Patient Protection and Affordable Care Act required the Department of Health and Human Services (HHS) to enlist the Institute of Medicine (IOM) in examining pain as a public health problem.

In the report that resulted from their examination, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*, the IOM committee recommends that HHS develop a comprehensive plan to:

- * heighten awareness about pain and its health consequences;
- * emphasize the prevention of pain;
- * improve pain assessment and management in the delivery of healthcare and financing programs of the federal government;
- * use public health communication strategies to inform people with pain on how to manage their own pain; and
- * address disparities in the experience of pain among subgroups of Americans.

Better Data Needed to Shape Efforts

Reliable data are lacking on certain under-diagnosed and undertreated populations. Health care federal and state agencies and private organizations should accelerate the collection of data on pain incidence, prevalence, and treatments for these populations:

- * racial and ethnic minorities
- * people with lower levels of income and education
- * women, children, and older people
- * military veterans
- * those with pain related to surgery and cancer; and
- * people at the end of life.

Defining Pain

The International Association for the Study of Pain defines pain as a subjective experience. This is a substantial barrier to treatment because pain “cannot be seen, like bleeding; it cannot be felt, like a lump; it cannot be heard, like a heart arrhythmia... and no current clinical tests for pain exist. People afflicted by pain may find the rough tools of language

inadequate to convey the character and intensity of their experience and its significance to them,” said the IOM.

In discussing the complexity of pain, the report rejects a simple biomedical approach, and includes the psychological, social, family, and cultural contexts of pain to understand and treat it. The fact that pain can persist long after tissue healing, that the nature of pain and its location can change, and that responses to therapy vary among individuals, support this approach. The report reviews how genetics, pain in childhood, neuromatrix theory (pain as an output of neural network), and emotional context can influence a person's response to pain. New neuroimaging techniques are leading to better understanding of the brain's role in chronic pain.

Care of People with Pain

Though people manage their pain in various ways and work with different specialists, for many, pain prevention, assessment, and treatment are inadequate.

Among steps to improving care, the committee recommends that healthcare providers and insurers should increasingly aim at tailoring pain care to each person's experience, and



People with Pain Speak Out

As part of their data collection and analysis, the IOM committee conducted a survey on pain care from Jan. 31, 2011 to April 5, 2011, solicited testimony from the public, and reviewed information in published sources. Here are some of the comments they gathered from people with pain.

I have a master's degree in clinical social work. I have a well documented illness that explains the cause of my pain. But when my pain flares up and I go to the ER, I'll put on the hospital gown and lose my social status and my identity. I'll become a blank slate for the doctors to project their own biases and prejudices onto. That is the worst part of being a pain patient. It strips you of your dignity and self-worth.

When they refused to treat me at the emergency room, they said, "We can't treat you for pain because we would be treating a symptom rather than the cause of a problem."

If I asked for prescription pain relief, I was treated like a common criminal. It was a terrible time in my life.

It is so much more than just pain intensity. Over time, many patients find the effects of living with chronic pain impact their ability to work, engage in recreational and social activities, and for some, [perform] the most basic everyday activities that people just take for granted. Not surprisingly, pain begins to chip away at their mood, often leaving them angry, frustrated, anxious, and/or depressed. Our families suffer along with us, and many relationships are forever altered.

A physician told me last week, "We don't usually prescribe any pain medication for fibromyalgia patients." My answer: "I'm surprised more of them don't commit suicide."

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self management of pain should be promoted. They suggest that primary care physicians and pain specialists should collaborate, particularly in delivering interdisciplinary pain assessment and care.

"Pain is more than a physical symptom and is not always resolved by curing the underlying condition. Persistent pain can cause changes in the nervous system and become a distinct chronic disease. Moreover, people's experience of pain can be influenced by genes, cultural attitudes toward hardships, stress, depression, ability to understand health information, and other behavioral, cultural, and emotional factors," the report states.

The report notes that a number of barriers—including regulatory, legal, institutional, financial, and geographical—limit the availability of pain care and contribute to care disparities. Government agencies, healthcare providers, and health care funders should unite to reduce or eliminate these barriers.

Educational Challenges

To improve public understanding of pain, federal agencies and other stakeholders should develop educational materials for people with pain, caregivers, and healthcare providers that:

- * Explain the complex biological and psychosocial aspects of pain,
- * Demonstrate self-help strategies to prevent, cope with, and reduce pain, and
- * Discuss the available treatments for pain.

They suggested that medical and health science college students should be offered standardized information about pain and gain experience in caring for people with pain. A recent study found that only five of the nation's 133 medical schools have required courses on pain and just 17 offer elective courses. Licensing and certification exams should include assessment of pain-related knowledge and capabilities. Programs that

train specialists or offer training in advanced pain care need to be expanded.

Improving education is especially important for primary care providers, given their key role in pain management.

Research Challenges

The IOM report brief states: "Research has made remarkable strides in understanding the biological, cognitive, and psychological underpinnings of pain, and the future promises advances in a number of fields—from genomic and cellular through behavioral mechanisms. Still, many gaps persist."

These challenges include:

- * Developing more effective and less risky pain relievers
- * Translating effective treatments from research into practice
- * Adapting the regulatory process to enable more efficient evaluation and approval of potentially effective therapies.

These research goals are complicated by the shortage of federal dollars for research, and that the responsibility for pain research is spread among many institutions and organizations.

Blueprint for Action

The committee recommends that the NIH should designate a lead institute for pain. It also recommends that the NIH Pain Consortium take a stronger leadership role.

The Institute of Medicine (IOM), the health arm of the National Academy of Sciences, is an independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision makers and the public.

You can read the entire report at the IOM website:

<http://www.iom.edu/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx>

The IOM Committee Tackles the National Problem of Pain

by Sean Mackey, MD, PhD, with Robert Kerns, PhD and Dennis Turk, PhD

More than 100 million Americans suffer from chronic pain, and the condition costs between \$560 billion and \$635 billion dollars a year in medical expenses and lost productivity, according to the National Academies' Institute of Medicine (IOM) report, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research*.

The IOM committee that produced the report concluded that effectively treating pain is a moral imperative that demands a cultural transformation on the part of physicians, other healthcare providers, people with pain and researchers. The final report presents a detailed blueprint and guidelines for public policy and for improving the state of pain care, education, and research in the U.S., and beyond to the global community.

Department of Health and Human Services (HHS) charged the IOM with assessing the state of the science regarding understanding of pain, pain management, and education and recommending how to advance the field in all of these areas. More specifically, the IOM was directed to:

- * Review and quantify the public health significance of pain;
- * Identify barriers to appropriate pain care and strategies to reduce such barriers;
- * Identify demographic groups and special populations, and discuss related research needs, barriers, and opportunities to reduce such barriers;
- * Identify and discuss what scientific tools and technologies are available;
- * Discuss opportunities for public-private partnerships in the support and conduct of pain research, care, and education.

The Committee Process

The IOM formed a 19-member committee (including three members of the ACPA Professional Advisory Committee, Robert Kerns, Sean Mackey, and Dennis Turk) representing multiple fields of medicine, ethics, epidemiology, psychology, and public health. We used a variety of methods to obtain and process information including literature reviews and public workshops. These public workshops allowed key stakeholders to advise us on their perspectives on the national issues related to pain. In these workshops we discussed data collection, public-private partnerships, cultural views of pain, financing and resources for pain care, basic science of pain and approaches to pain treatment, regulation of pain drugs, and gathered personal testimony from people living with pain, their caregivers, and other stakeholders.



The IOM report on pain presents a detailed blueprint on how to improve the state of pain care, education, and research in the U.S. and more globally.

We received public input through a website and read through over 2,000 responses. The Committee commissioned an analysis of health care costs and prevalence of pain in the general population from Johns Hopkins University to gather better assess pain's economic burden.

Seven Underlying Principles

The Committee was guided by several underlying principles in developing the final report.

- * Pain management is a moral imperative and needs to be better assessed and treated—and this is better accomplished using interdisciplinary and comprehensive approaches.
- * While pain is often a symptom of a disease, when pain becomes chronic it can become a disease in itself.
- * There is already a large amount of existing knowledge about effective pain treatment that we need to better disseminate.
- * Pain is better prevented than treated and we need to direct more resources at effective prevention of chronic pain.
- * There is a clear conundrum regarding opioids and the Committee called for a view that balances the beneficial effects with the potential adverse consequences.
- * We need improved collaboration between patients and clinicians.
- * There is strong value in applying public health and community-based approaches to pain care.

The IOM Committee called for a cultural transformation in how we prevent, assess, treat, and understand pain.

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The IOM report specified that 116 million Americans experience pain and calculated that \$560 billion to \$630 billion is spent each year on direct and indirect medical costs. But it also made clear that pain is a uniquely individual and subjective experience—one that is often not directly related to the amount of tissue damage or injury observed.

Due to the complexity and challenges in treating chronic pain, a comprehensive and interdisciplinary (e.g. biopsychosocial) approach is the most important and effective to pursue. Unfortunately, such care is difficult to obtain because of structural barriers such as financial and payment disparities. Consequently, the Committee called for a “cultural transformation” in how government agencies, private foundations, health care associations and payors, health care professionals, patients, and the public prevent, assess, treat, and understand pain and offered a blueprint for achieving this transformation.

Recommendations and Timetables

The Committee offered 16 recommendations in four key areas: public health challenges, pain care, education of providers, and research. The blueprint designated these four to be accomplished by the end of 2012.

- * The Secretary of Health and Human Services should create a comprehensive population-level strategy for pain prevention, treatment, management, and research. This should include:
 - conduct coordinating efforts across public and private sectors
 - a research agenda for developing research
 - improved pain assessment and management programs
 - ensuring that the Interagency Pain Research Coordinating Committee and the NIH Pain Consortium (a group of NIH institutes with an interest in pain) cooperate in reaching out to private-sector participants as appropriate
 - Enhancing public awareness of chronic pain.
- * HHS and other entities including the Veterans Administration, the Department of Defense, and large health care providers should reduce barriers to pain care, especially for populations disproportionately affected by and undertreated for pain.
- * They should enlist pain-specialty and primary-care professional organizations in supporting collaboration between pain specialists and primary care clinicians and educate primary care providers as to when to refer patients to pain centers.
- * Ask NIH to designate an existing institute that includes pain as a central part of its mission as a lead institute responsible for advancing pain research—including assessing NIH’s overall effectiveness in this area, assuming leadership of the Pain Consortium and increasing its scope, and identifying funding needs. Furthermore, it should require the Pain Consortium to:
 - conduct more frequent, structured, and productive meetings
 - improve the process for reviewing pain-related grant proposals
 - work with pain advocacy groups to help identify public need related to treatment and management; and
 - improve and expand public-private partnerships.

Some have asked why the Committee did not address other, equally important aspects of pain, such as our national problem of chronic prescription opioid misuse and abuse or the formation of a national institute of pain. The Committee acknowledged and described the problem of opioid misuse and abuse, however an in-depth examination with specific recommendations was beyond the Committee’s charge. Likewise, the Committee discussed in its report the creation of a “pain institute” at NIH, and concluded that at this time it is not a viable option.

The IOM report on pain presents a detailed blueprint on how to improve the state of pain care, education, and research in the U.S. and more globally. It creates a timely and important opportunity that should be seized by the ACPA as a potential way to reinforce and further its mission.

Find the complete IOM report, including its executive summary at <http://www.iom.edu/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx>.

Sean Mackey is Associate Professor, Departments of Anesthesia, Neuroscience and Neurology; Chief for the Division of Pain Management, Stanford University School of Medicine. Robert Kerns, PhD is VHA National Program Director for Pain Management, Director of the Pain Research, Informatics, Medical comorbidities, and Education (PRIME) Center at the VA Connecticut Healthcare System, and Professor of Psychiatry, Neurology, and Psychology at Yale University. Dennis Turk is the John and Emma Bonica Professor of Anesthesiology and Pain Research and Director, Center for Pain Research on Impact, Measurement, & Effectiveness (C-PRIME) at the University of Washington School of Medicine in Seattle.

Patient-Centered Care: Essential for a Successful Journey from Patient to Person

by Dan Cherkin, PhD

When I began conducting research on back pain 26 years ago, I knew nothing about it. I had never experienced back pain nor read any articles on the topic. In retrospect, my ignorance may have been ideal preparation for bringing a fresh view to the problem, one unencumbered by training in a particular clinical or conceptual perspective. Let me explain.

After completing my PhD in epidemiology, I joined the faculty of the department of family medicine at the University of Washington. During my seven years there, I learned about the importance of the “biopsychosocial model” for understanding patients as whole persons whose health and responses to illness were affected not only by the diseases or conditions they experienced but also by the psychological and social circumstances in which they lived.

I also learned that there were serious deficiencies in the training of family physicians in some areas, especially care for chronic musculoskeletal pain conditions. This deficiency resulted from the mismatch between the types of people included in the research studies conducted by those considered to be experts on back pain (surgeons and pain clinic psychologists) and those seen in primary care settings. As a result, the training in back pain that primary care physicians received did not apply to the types of patients they saw. This has led to tremendous frustration for both primary care physicians and people with back pain. It is at the root of many of the problems with care for back pain that have emerged in the past few decades.

Additional Factors Influence Care

Ineffective delivery of back pain care was further compounded other factors.

- * The rise of “high-tech low-touch” medicine promoted advanced diagnostic and therapeutic technologies without clear evidence that their use led to improved outcomes.
- * The explosion in these technologies was fed by a reimbursement system that incentivized physicians to use them.
- * The same system discouraged physicians from spending time listening to their patients and partnering with them to find solutions to their problems.
- * Finally, the shortage of primary care physicians has resulted in increased stress and burn-out in many physicians and less time to spend with each person in their care.

Collectively, these circumstances have led to a diminished ability of primary care physicians to meet the needs of many people with back pain (and other conditions).

Recent research confirms that despite greatly increased expenditures on medical care for back pain (largely for expensive diagnostic tests and invasive treatments), the amount of disability from back pain in the U.S. population has increased. Clearly, we have been heading in the wrong direction, and need to radically rethink what we are doing.

The limitations of the current approach is underscored by the large and increasing number of persons with back pain who seek care from complementary and alternative (CAM) practitioners. In fact, back pain is the most common reason for seeking care from CAM practitioners such as chiropractors, massage therapists, and acupuncturists. Although none of these treatments works for everyone, many persons with back pain who have not had their needs met by traditional medicine have found relief from CAM practitioners. Why is that?

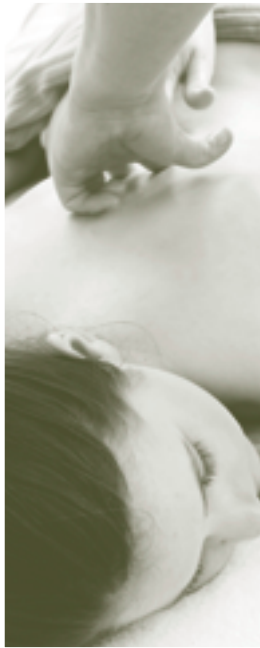
What Makes the Difference?

Why have CAM treatments succeeded when conventional medical care has failed? Some reasons may be the amount of time CAM practitioners spend with their patients, their positive attitudes about working with persons with back pain and beliefs in their ability to help, and their training in techniques that are effective for back pain. Our research has consistently found treatments such as acupuncture, massage, and yoga are more effective for chronic back pain than the types of treatments offered by medical doctors.

However, our research and that of others, has also found that the “non-specific” effects of these treatments may be as or more important than the “specific” effects. For example, we found that superficially stimulating acupuncture points with toothpicks is just as effective as inserting real needles—at least for persons without prior experience with acupuncture. In another study, we found that full-body relaxation massage was as effective as massage of the specific structures of the back that the therapists believed were responsible for the pain. How should we interpret these findings?

There are two ways to interpret research findings that show that treatments delivered in a therapeutic context may be effective even if the specific component believed responsible for their effectiveness is missing.

1. The hypothesized rationale for the treatment’s effectiveness is incorrect. Thus, in our acupuncture trial, it is possible that superficial stimulation of acupuncture points caused in the same (or different but comparable) physiological response that resulted from actual insertion of needles. In this interpretation, acupuncture would be considered effective, but not for the expected reasons.



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2. The stimulation of acupuncture points had no effect. Instead it was something about the clinical experience of receiving care from an acupuncturist that had positive effects. This could include a welcoming and caring approach, the acupuncturist's confidence that acupuncture could relieve the pain, the time the person with pain spent relaxing on a comfortable table, or other "non-specific" factors.

Of course, both interpretations could be valid, that is, the specific effects of stimulating acupuncture points AND the "non-specific" effects of the broader treatment experience contributed to the observed benefits of acupuncture: less pain and improved ability to function. But, does it matter which interpretation is the correct one?

Finding a Safe Treatment Most Important

We do not know how much each of these possible interpretations contributed to the positive effects of acupuncture. From the perspectives of those giving and receiving care, finding a safe treatment that relieves suffering may be more important than knowing why the treatment worked.

However, the interpretation gets a bit more complex from the perspectives of researchers and policymakers who are concerned about whether the effects of a treatment are "real" or "only a placebo." Such a distinction is clearly important for the FDA when deciding whether or not to approve the sale of new drugs which typically have some risks (some of which are not initially known) and may be very expensive when first introduced.

But this distinction does not seem to apply well to physical treatments such as acupuncture, massage, and yoga. How would one create a plausible "placebo yoga" treatment—one that resembles yoga but doesn't include its active ingredient (which is unknown and probably includes many interacting facets)? Until someone figures this out, we will not be able to determine what proportion of the effectiveness of a physical treatment is due to "specific" versus "non-specific" effects.

In the meantime, we need to provide persons with back pain access to all the safe treatments that have been found effective. In fact, acupuncture, massage, yoga, and spinal manipulation (mostly chiropractic in the U.S.) are included among the treatments recommended for persistent back pain by an expert panel co-sponsored by the American College of Physicians and the American Pain Society.

Solution to Chronic Pain as Complex as Pain Itself

Here are what I consider the most important lessons learned from 26 years of primary care-relevant research on back pain:

1. The context in which care is provided to persons with back pain likely has a substantial effect on treatment outcomes. Therefore, allowing patients to tell their stories, validating their pain experiences, and partnering with them to find solutions to their problems are important parts of a successful treatment process.
2. Chronic back pain is a complex problem involving a mix of physical, psychological, emotional, and social factors. Because these factors are inextricably intertwined, trying to understand them as distinct phenomena is unlikely to be helpful. It would be better to acknowledge that all of these factors are involved to varying degrees in every person with pain and that the best approach will need to be tailored to each one's individual needs and circumstances.
3. Many primary care physicians feel they have little to offer people with back pain. However, because a variety of treatments have been found effective, physicians can honestly offer hope of relief by partnering with their patients to find one that works.
4. Although we now know enough to substantially improve care for back pain, there are major systemic barriers to change. These include reimbursement policies that favor clinician use of procedures over partnering with patients, inadequate training of physicians in the management of pain, and the long delays in implementing research findings into practice.

The good news is that there is an increasing recognition of these barriers and creative efforts to overcome them have begun to emerge.

Dan Cherkin is a senior scientific investigator with the Group Health Research Institute in Seattle. His graduate training was in research methods as he attained an MS in Biostatistics and a PhD in Epidemiology, but his 30+ year research career has focused on identifying ways to make primary care more responsive to patients' needs. He has concentrated on trying to understand why medical care has failed to meet the needs of so many persons with back pain and evaluating the value of complementary and alternative therapies including acupuncture, chiropractic, massage, and yoga.

ACPA Updates



Global Year Against
HEADACHE
Oct 2011 - Oct 2012

Global Year Against Headache

The 2011-2012 Global Year Against Headache campaign, sponsored by the International Association for the Study of Pain (IASP), will draw attention to one of the most common, painful, and disabling conditions that affect people throughout their lives: the headache. IASP worked with the International Headache Society to develop fact sheets on different headache types and classifications, the epidemiology of headache, and approaches to study and treatment. They are available free in five languages on the IASP website:

www.iasp-pain.org/GlobalYear/Headache.

The campaign, which will run through late October 2012, will include meetings, symposia, patient-education events, and media efforts to highlight the latest research techniques on headache, ways to address various types of headache pain, and genetic factors leading to headache. Contact IASPdesk@iasp-pain.org for more information.

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Local, state, and national government representatives helped recognize Pain Awareness Month around the country in September 2011.

Ernie Merritt, regional director and facilitator of the ACPA support group in southern Maine, shared a letter from U.S. Senator Olympia Snowe. The senator said, in part, "I extend my heartfelt appreciation for the crucial efforts by the Chronic Pain Support Group of Southern Maine and many similar advocacy organizations in both raising awareness...and providing vital support to those afflicted with chronic pain."

Sen. Snowe is a staunch supporter of medical research at the National Institutes of Health, which funded \$360 million in projects dedicated to pain research last year. She called this research critical in light of the medical and economic costs related to pain. She concluded by saying, "Your unwavering commitment as devoted and strong advocates here in Maine and in Washington to those who are confronting chronic pain is to be applauded many times over."



Members of Merritt's support group are pictured here in their ACPA shirts, with some government representatives wearing ACPA lapel pins. Back row, Nancy, Mayor Michaud, Rep. Don Pilon, Rep. Linda Valentino, Tom Arnold, Deputy of Motor Vehicles, and Peter Morin, regional representative for Sen. Snowe. Front Row: Lois, Bill, Shirley, Evelyn, John, Ernie, Rose, and Ann Goodridge from Senator Pingree's office.

Welcome to our new groups and facilitators.

Chelsea Nann
Marin County, CA

Ron Rich
Lakeland, FL

Carol Orton
West Palm Beach, FL

Leona Harter
Baxley, GA

Tina Stephens
Dubuque, IA

Jessica Hartley
Madison, IN

Keith Cooper
Chicago, IL

Lindsay Baran
Chicago, IL

Patricia Grant
Nottingham, MD

Joseph Bougie
Eagan, MN

Keith Landsman
West St. Paul, MN

Susan Huber
White Bear Lake, MN

Margaret Morton
Cleveland, MS

Ron Powell
Tupelo, MS

Maria Kleine
St. Louis, MO

Lindsey Saullo
Jamestown, NY

Linda Highben
Canton, OH

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ACPA Annual Meeting

The ACPA Board met in Pittsburgh, Pennsylvania for their annual meeting on October 22.

In reviewing the past year, board members learned that ACPA has intensified its efforts to connect with people with pain and serve as their voice at educational, professional, and legislative conferences.

Support groups across the U.S., and also in Canada, Ireland, Australia, Brazil, Argentina, Uganda, and Scotland, are led by people with pain who are reaching out to let others know “you are not alone.” ACPA facilitators were given media training and many became involved in community outreach.

In 2011, ACPA continued to provide tools to help with pain management and improve communications between people with pain and health care providers. Several pain logs have been updated as interactive, online tools that let people track and report their pain over time.

For the second year, Blue Cross/Blue Shield of North Carolina is using ACPA tools for administrators and employee groups. Our pain management tools were also used by Quentin Mease Community Hospital in Houston, TX after Hurricane Katrina to help people deal with their pain until they could get their medications again. The “Medication Safety PSA” is now being played for people “on hold” in calls to Kaiser Permanente.

In July 2011, the fifth ACPA Corporate Roundtable was held in New York City to discuss future projects, including: expanding Growing Pains (for adolescents); continued outreach to veterans groups; more Maze of Pain interactive, online learning units; additional videos for the Pathways through Pain series and the opioid safety campaign; and putting pain management tools on DVDs and mobile phones.

In 2012, ACPA will exhibit at Pain Week 2012 (a conference for frontline clinicians with an interest in pain management), attend the American Academy of Family Physicians meeting, and present to Pain Fellows in the Pain Management Program at Stanford Hospital and Clinics.

At the meeting, Dr. David Provenzano became past-president, Dr. Andrew Bertagnolli was elected president, Daniel Galia was re-elected as treasurer, and Joanne Schneider as secretary. The board members reviewed and approved the financial statements for 2010-11 and adopted a budget for 2011-12.



Mariann Farrell, facilitator for the ACPA Support Group in Pittsburgh, Pa., holds the proclamation by which City Council recognized September as Pain Awareness Month in the City of Pittsburgh.

Transforming Pain Management

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In addition, we cannot forget about the conundrum of using opioids to manage moderate to severe pain. Many issues must be addressed if we are to win the war on pain. Yes, it is a war for people with pain to fight to get appropriate care, to be validated, to be given hope for a better tomorrow. I firmly believe that this IOM report will provide us with ammunition to move our campaign forward. We—you and me—need to continue our efforts to support the need for better education, better access, and most importantly, increased understanding about living with pain.

Since the IOM report was published, there have been a number of coalitions formed, meetings held, and initiatives launched to ensure that the document is not forgotten. It is our war and each one of us must do our part to ensure victory over pain. Your voice matters. Your story provides the real story of pain. Moreover, your journey from patient to person will not go unnoticed. You are the essential part in our efforts and the reason we persist!

In this issue, we will look more closely at the IOM report. As an invited reviewer of the report, I can say that it was one of the most encouraging documents on pain that I have read in my 31 years of working with the American Chronic Pain Association. I hope that you will take the time to read at least the summary that can be found at <http://www.iom.edu/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx>.

The IOM report did not win the war, but it certainly was victorious in a major battle. Now we must continue to move forward knowing that there is indeed hope for a better tomorrow.



Veterans In Pain Can Find Answers through ACPA

by Jani Larsen

As a veteran and coordinator of the Veterans in Pain (VIP) program, I would like to invite all veterans to get involved in the emerging VIP program.

VIP was developed by the American Chronic Pain Association (ACPA) out of the understanding that veterans have different issues than the general population when it comes to pain, and that it affects us differently. The VIP's motto is "Because we understand..." meaning that veterans can best help other veterans cope with chronic pain.

Penney Cowan, Executive Director of ACPA, has been speaking at many Veterans Health Administration hospitals throughout the nation and one theme is very clear: we need to help educate physicians and people living with chronic pain. You can view her talk with veterans on the ACPA website, www.theacpa.org.

The VIP program brings the excellent ACPA pain management materials and facilitators to the veterans wherever they may be.

Part of the program allows veterans who are housebound or who have transportation issues to communicate and learn about managing and coping with chronic pain via the Internet. Facilitators will guide online support groups of six to eight individuals through the ACPA workbook, *Patient to Person, First Steps*. An interactive presentation by the facilitator will encourage veterans and promote a healthier lifestyle through pain management and coping. At the end of the presentation, the facilitator will answer questions from the group via a chat session.

Participants can be anonymous, however, they will have to register and answer some simple questions to verify themselves as veterans. **Phone 1-800-533-3231 to be reviewed and verified.**

VIP also has a very informative website, www.VetsInPain.org, developed to allow U.S. military personnel and veterans access to ACPA's peer support groups. Special thanks goes to Endo Pharmaceuticals for supporting the redesign of the website for improved functionality.

We encourage all veterans to contact their local VA health care facilities and volunteer to facilitate a VIP group. There are many other ways for veterans to help veterans—just email me at taboga@me.com and I will add you to our planning committee where you can give direction for this ever expanding group of veterans.

We are very excited to have this opportunity to offer the excellent pain management guides, communications tools, and materials based on the philosophy of the ACPA to our nation's heroes.

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Members' Forum The Road Less Traveled

by Gerald Becker, ACPA Chapter of New York City/Westchester

When an unexpected event or series of events profoundly and positively alter your life experience, we call this serendipity. Such was the case 25 years ago, at the age of 44, when suddenly and mysteriously I was confronted by the challenge of chronic pain in the lower back, eventually diagnosed as a part of myofascial pain syndrome. I spiraled out of control as far as any human being could travel!

Through the intervention of a remarkable pain rehabilitation facility in South Beach, Florida, and an incredibly patient and supportive wife, I improbably and literally got back to the light. Thus began my serendipitous journey down the road less traveled.

Once a highly athletic and self-possessed individual in complete harmony with my body, I now found myself in the frightening world of disability. Yet once the betrayed body and mind recovered, an amazing series of transformations occurred. I was somehow able to translate the intensely competitive skills I had learned through sports into the far more challenging world of being a supportive caregiver.

I doggedly pursued the difficult goal of becoming an ACPA facilitator in the New York City area. I achieved success and directed a group of many very different individuals on the very draining journey from patient to person. This group ran for over 15 years.

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A Helping Hand: A Winter Tale of True Community

by Penney Cowan

It was late winter. The days were already extending their light into early evening. Most folks around town were pretty happy to be sitting at home enjoying their creature comforts during the cold winter days. In these parts, it was difficult to do much else because of all the ice and snow. A normal winter could dump up to a hundred feet of snow. Yes, riding out the winter on the davenport was tradition in this small town nestled in the Colorado Rocky Mountains.

Not much was expected of anyone from November—when the snow began to fall—until late April—when the first thaw gave promise that the winter would not last forever. One hundred and twenty-three people lived in this small town. They had a system to make sure that a day didn't go by without every household being contacted. It was important to keep tabs on folks since the winters were brutal and the snow was never-ending. It was not unusual to have a roof cave in or water pipes freeze, unwilling to release their contents until the first warm days in May. It was part of the responsibility of being a member in this community to ensure everyone was making out okay.

At 10,000 feet, this desolate mountain town sat high up on the Rockies. One would think that the isolation and loneliness of living in such a remote area might make people stand-offish, unfriendly. But the people in this town were committed to one another. If anyone in the community got sick, had problems with their home, ran out of supplies, the town's people were right there to lend a helping hand. If there was ever a community spirit, this community had 110% of it.

This place was called Torn Dress, Colorado. The town was renamed after an incident about 20 years ago.

That evening, a young woman struggled through the snow, the temperature -20 degrees. The wind was howling, the snow was blowing and the wind chill factor hovered at -30 degrees. It was a night not fit for man

or beast. But there, in the middle of a blizzard, was a frail young woman with nothing more to keep her warm than a torn dress, the entire back ripped away. She was just standing in the road, her cries for help inaudible through the windows sealed against the cold winter night.

Thor, a widower in his late 70s, just happened to glance out his window about the time the woman was losing her fight against the elements. At first glance, she almost looked like his late wife. He thought to himself, "that could be my Emily standing out there. I've got to help." So, Thor grabbed a heavy blanket and bolted out the door. By the time he got to the young woman, she was almost buried in the snow. He struggled to get her to her feet and helped her into his house. He sat her down in the rocker, close to the fire and went to the kitchen to fix her a warm cup of tea. The whole time he kept asking himself what would make her go out in the winter like that without even a coat on? What was she looking for?

"Here you are, missy. I think the warm tea should help. Always helped my Emily."

"Thank you kindly, sir." Her lips chattering as she spoke. "I don't want to be any trouble."

"Not at all. Mind if I ask you a question?" Thor just couldn't help himself, he had to know. "Why in blazing bullets were you out there like that? If I hadn't come out to get you, you would have surely frozen. What was so important to risk your life?"

The young woman sipped at her tea for a moment, staring into the fire. "Well," she said, "I have lived here for about three years now. Just about a half mile down the road. I have two children who depend completely and totally on me. The storm knocked out our generator and so we had no heat. My phone isn't working either, so I couldn't call anyone. I knew we only had enough firewood to make it through the night. I made a big fire, gave the kids dinner and decided to go for help.

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The Road Less Traveled

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I can't remember all the churches and synagogues I pleaded with to use a meeting space.

Eventually health issues forced me to move it online, where it is still running. Through this online forum I talk to people all over New York City who are on the edge; often I feel like I am on a suicide prevention hotline!

I was interviewed on TV and talked to church groups to enlighten others about the epidemic of chronic pain. I currently volunteer at a local nursing home. Improbably, I am able to listen and respond to the residents' needs with an ability that would have been impossible before I experienced my own vulnerability.

Of course, I am not implying that it takes intense personal suffering to learn that a complete life demands not only self-love, but love and compassion for others. But if your mind, body, and soul are open to it, out of the chaos that is chronic pain you may reach new heights and develop amazingly wondrous inflorescences. Discovering that good fortune was my serendipity.

Let me share an experience even more dramatic than my own. Lying awake one night feeling anxiety about an upcoming trip to Africa, I heard a loud drumming on the TV at 2:30 a.m. I became hypnotized by a young man on a motivational talk show giving a virtuoso drum solo to a wildly cheering audience. This musician had undergone 80 burn surgeries that had forced the loss of both hands, yet he would not let the trauma dissuade him from sharing his genius with the world.

Out of his cauldron of chaos, the chrysalis of suffering, what a unique and beautiful butterfly flew.

I hope this is a lesson for so many of us who think all roads are forever blocked when chronic pain strikes. I urge you to consider the serendipitous detours and discover a new path.

A Helping Hand

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"I knew if I didn't find someone who understood what it meant to have no heat up in these mountains, we would surely die. I trudged through the snow pretty well until my coat got caught on some trees and then I slipped down a hill. That was about 50 yards back or so. But I'm strong; I knew I would make it even without my coat and with my dress torn. But, I never counted on the isolation of this place being so immense. You are the first person that I've seen since I began my journey. I guess the snow made it impossible for me to see much of anything. By the time I got to your house the wind let up enough for me to see the house. All I need is some help getting the generator going. I can pay you for your help."

"Nonsense! You ain't pay'n me a red cent, missy. I'd be more than happy to help."

So after that night, the word got around the small village that there was a real need to have everyone pull together and to care for one another. No one really thought much about it until that cold snowy night. But, once they became aware of how much they needed each other, things changed.

It began in late spring of that year when they held their first community barn dance. There were only two business items—besides the dancing, that is. One was to appoint a committee to design a system to ensure that each house in the village was contacted each day during the winter. The other was to rename the town. The only name suggested was Torn Dress, Colorado, a simple reminder to everyone of how much they depended on each other and how vital each person is.

I am sure that you realize that the ACPA is very similar to Torn Dress, Colorado. There is a community of people all over the world who depend on each other through the ACPA, who depend on you to make sure they matter at the end of each day. People in pain need to know that there is someone to help them, someone that cares and that someone really understands what living with pain means. Know that the American Chronic Pain Association will always be here for you!

Book Review

How To Be Sick: A Buddhist-Inspired Guide For The Chronically Ill and Their Caregivers

by Toni Bernhard

Review by Tara White, RN

Through her gracious and inspiring prose Toni Bernhard has managed to find a way to prove to those of us with chronic pain or illness that there is dignity in being ill. Using inspiration from Buddhist teachings, she weaves them together to help us first accept our present circumstances, and secondly, meet the difficulties of day-to-day life with a trusting nature while cherishing the abilities we do have.

While on a trip to Paris celebrating her 20th year as a law professor at the University of California at Davis, Dr. Bernhard fell very ill from a mysterious virus. Not only did it severely jeopardize her vacation, it ended her career and ultimately forced her to retire. Numerous tests and physicians later, she was unable to even leave her bedroom for long. The virus stole her energy, strength, and stamina for the life she once lived. Forced to accept her new circumstances, yet remaining determined to regain enjoyment in life, she turned her interest in meditation and Buddhism into a coping mechanism. She ultimately wrote this book from her bed to help others and their caregivers use this strategy to deal with similar life altering illnesses.

The reader learns to deal with life from a new perspective, utilizing acceptance and wisdom. The author's advice is intended to help readers to:

- * cope with symptoms that just won't go away
- * come to terms with a more isolated life
- * weather fear about the future
- * face the misunderstanding of others
- * deal with the healthcare system; and
- * help their spouses, partners, or other caregivers adapt to so many unexpected and sometimes sudden life changes.

I was very impressed with how Dr. Bernhard accomplishes her goals with gentle, loving Buddhist teachings, meant for those of any spiritual or religious background. It is not only easily readable, but also very hard to put down.

Beginning with acceptance, Dr. Bernhard quotes the great Zen master Eihei Dogen: "Without the bitterest cold that penetrates to the very bone, how can plum blossoms send forth their fragrance all over the universe?" Life is unpredictable and unknown, yet without the "cold" of illness, many of us would miss "smelling the flowers," appreciating this slower pace life has forced upon us.



While Buddhist teachings encourage acceptance of difficulties, it also reminds us that happiness and joy are part of life as well. Furthermore, while Buddha teaches that bodily pain is an inescapable part of the human condition, the suffering of the mind is not. There we have a choice.

This choice reflects the study of mindfulness. Mindfulness is the ability, achieved over time with practice, of paying careful attention to what is happening in the present moment. Despite our ongoing chronic pain, sights, a sound, a taste, a smell, a sensation in the body, or thoughts and emotions are also competing with our minds for our attention. The author offers several beautifully descriptive practices to help us stay in the moment.

Additionally, the reader is taught to use loving kindness to not only accept, but cherish one's body as a way to promote the end of suffering. We must learn to cultivate compassion for ourselves. Phrases such as "Be peaceful, sweet body, working so hard to support me," help us create a shift from suffering to nurturing. She eloquently takes us on a journey of transforming any difficult thoughts or situations into more acceptable and calming reflections. This is a very powerful mind tool to use as the need arises.

My favorite quote is from Thai Buddhist monk Ajahn Chah:

"Let things take their natural course.

Then your mind will become still in any surroundings, like a clear forest pool. All kinds of wonderful, rare animals will come to drink at the pool....

You will see many strange and wonderful things come and go, but you will be still. This is the happiness of the Buddha."

As Dr. Bernhard describes the beginning of her acceptance of her illness, "I began to bow down to these facts, to accept them, to be them. And from there, I looked around to see what life had to offer. And I found a lot."

When you read her book, you cannot help but come away with a new perspective and awareness of life's beauty to enjoy despite chronic bodily pain. The choice of inner peace and compassion is available to all of us. I found a lot to embrace in this lovely work of art.

How To Be Sick: A Buddhist-Inspired Guide For The Chronically Ill and Their Caregivers; author, Toni Bernhard; Wisdom Publications, 192 Pages, \$15.95, ISBN 978-0-86171-626-5, www.wisdompubs.org

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Welcome to our new groups and facilitators.

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Please send inquiries to:
The ACPA
P.O. Box 850
Rocklin, CA 95677

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