Once upon a time there lived a man named Jack. He was a very determined person who never started anything unless he knew he could finish it. He was very particular about the work he did. He was a believer in the idea that if you are going to do something, it was worth doing right or not at all. So, when it came time to build his dream house, he carefully laid out his plans. First he would dig the foundation. He would work the months of January and February on this. Jack knew that for any house to remain solid and dependable, it needed a strong foundation. He dug and dug until he was satisfied that the foundation would not only support the house, but would weather all kinds of storms. He took his time to ensure that the foundation would not fail, causing the house to crumble. His foundation took a little longer than expected and he was not ready to begin the frame for his house until mid-March. Carefully over the next few months, he managed to build the outside walls. He knew that by using extra heavy building materials, he could build a strong frame that would withstand extra weight and pressures. As he paused to review his work, he was pleased with his progress. He knew that if each phase of the house was correctly constructed, the end result would be a house in which his family would feel safe. Next, he worked on the individual rooms. He worked at a steady pace and knew when he had worked long enough each day. He took care not to get overly tired, knowing that he could become careless and invite accidents if he pushed himself past his limits. Jack wanted his house to be a place of pride to showcase his abilities as a builder. He was willing to extend his time schedule when it was clear something was not going as he planned. Before long, he was ready to install all of the electrical and plumbing fixtures in the house. It took until mid-May for him and his family to select and install the light fixtures for each room. He and his wife looked long and hard before they found just the right cabinets, stove, sink, and countertops for their kitchen. Even the bathroom fixtures were a joint decision for both of them.

CONTINUED ON PAGE 12...
Strong pain-killing medications such as OxyContin, Avinza, Dolophine, and Duragesic are in the spotlight this year, due to a new requirement from the U.S. Food and Drug Administration (FDA) that manufacturers provide more physician and consumer education about them.

These medications—which, with ongoing medical monitoring, can be used successfully by some people to manage chronic pain—are also among the most commonly abused prescription medications. In April 2011, the FDA first announced the elements of a Risk Evaluation and Mitigation Strategy (REMS) to ensure that the benefits of extended-release and long-acting (ER/LA) opioid analgesics outweigh the risks.

The FDA estimates that 23 million people were prescribed ER/LA opioid medications in 2011, with more than 320,000 prescribers writing at least one prescription for opioids.

In 2010, 35 million Americans ages 12 and up reported non-medical use of opioid analgesics, up from 29 million in 2002.1

On July 9, 2012, the FDA approved a REMS for 30 ER/LA opioid medications produced by 20 pharmaceutical companies. Key components of the REMS include:

- Training for prescribers
- Updated Medication Guide and patient counseling document
- Assessment/auditing

There is no mandatory requirement that prescribers take the training and no precondition to prescribing ER/LA opioids to patients. However, the first continuing education activities under the REMS were expected on March 1, 2013.

What Does the REMS Mean to You?

Many people with pain are wondering if REMS will make it harder to get their pain treated. As part of the process the FDA says it will monitor patient access to pain medicines and will continue to talk with the community of patients with pain and prescribers to ensure that patients get proper pain management.2 They do not expect that this action will affect patients’ access to their pain medicines.

The REMS requires opioid manufacturers to educate healthcare providers (HCPs) about proper prescribing procedures. These pharmaceutical firms are responding by providing grants to continuing medical education (CME) providers, healthcare associations, and others to offer training on this topic.

Prescriber education is to be based on the FDA Blueprint for Prescriber Education for Extended-Release and Long-Acting Opioid Analgesics’ released in 2013 and includes information on weighing the risks and benefits of opioid therapy, and recommends that careful monitoring be considered.

In addition, according to the FDA, the education will include “counseling patients on the safe use of these medications, how to recognize evidence of, and the potential for, opioid misuse, abuse, and addiction, and general and specific drug information for ER/LA opioid analgesics.”

Which Medications are Affected?

Opioids—so named because they are synthetic versions of opium—are narcotics that work by changing the way the brain perceives pain. They are available in forms that include pills, liquids, and skin patches.

ER/LA opioids are more of a safety concern than immediate-release formulas because they are stronger and either stay in the body longer or are released into the body over longer periods of time. The medications that will be required to have a REMS include:

- Avinza
- Butrans (transdermal buprenorphine)
- Dolophine (methadone)
- Duragesic (transdermal fentanyl)
- Embeda
- Exalgo (hydromorphone)
- Kadian
- MS Contin
- Opana ER (oxymorphone).
- Oramorph (all morphines)
- OxyContin (oxycodone)

The FDA states that “companies will be expected to achieve certain FDA-established goals for the percentage of prescribers of ER/ LA opioids who complete the training, as well as assess prescribers’ understanding of important risk information over time. The assessments also cover whether the REMS is adversely affecting patient access to necessary pain medications, which manufacturers must report to FDA as part of periodic required assessments.”

One of the first educational tools was produced in October 2012 by The Office of National Drug Control Policy (ONDCP) and the National Institute on Drug Abuse (NIDA).3 This online CME course provides “practical guidance for physicians and other clinicians in screening patients for substance use disorder risk factors before prescribing, and in identifying when patients are abusing their medications.”
A Reminder to Behave

“On one side we have the ever-increasing problem of deaths and dysfunction from the inappropriate use of prescription opioids, and on the other we have the needs of people for adequate pain control to facilitate comfort, activity, and function,” said Steven D. Feinberg, MD, Adjunct Clinical Professor, Stanford University Pain Service. He is a physiatrist and pain specialist in private practice in Palo Alto, California and on the ACPA Board of Directors.

Dr. Feinberg states that there are many other tools to manage pain, like those taught by the ACPA, but not everyone has access to a pain specialist, psychological care, or a good pain rehabilitation program. In addition, there is at times a lack of insurance coverage for psychological pain management and physical therapy. “These tools are harder to learn, harder to make part of a day-to-day pain management regimen, but they improve function and quality of life without side effects and risk of abuse,” he said.

Dr. Feinberg expects that REMS, along with negative press about opioid abuse, will increase awareness of the problem and make some HCPs more thorough when prescribing high-dose opioids. “REMS will remind HCPs to do more thorough patient examinations and histories. This could result in them not prescribing to people who are more likely to develop opioid related problems including misuse, abuse, and addiction,” he said.

Identifying Repeat Users

Building awareness is also the goal of prescription monitoring programs that have been used in some states to identify HCPs who frequently offer opioids and to stop abusers from doctor-shopping for multiple prescriptions. When HCPs were able to get real-time data on multiple prescriptions for a patient, some studies show, they change their opioid prescribing patterns.

Dr. Knox H. Todd, MD, MPH of Beth Israel Medical Center, New York, suggests that these programs offer promise and that more controlled research needs to be done. “The ED (emergency department) is an appropriate site for screening intervention and prescription monitoring programs are a welcome tool in our arsenal,” he said.

“Unfortunately, emergency physicians do not receive much training in recognizing patients with the potential for substance abuse. The hectic nature of emergency medicine means we cannot precisely characterize patients with complex pain complaints, and might lump legitimate pain behaviors with the ploys of drug abusers. REMS could be welcome as an additional force for more education,” he said.

Consumer Education for Safety

REMS requires consumer education (CE) materials that emphasize safe practices, such as:

- Getting regular monitoring and advice from a HCP, and always before changing doses
- Preventing exposure to family and visitors
- Keeping prescription drug use confidential
- Never sharing prescriptions
- Storing pills securely and disposing of them correctly
- Learning the signs of potential overdose
- Keeping emergency contact information handy

“Education is a part of the solution to opioid abuse,” said Jennifer Bolen, JD, founder of The Legal Side of Pain, an educational company dedicated to addressing advocacy and policy issues on controlled substance prescribing.

“People with pain must be smarter about how they handle their medications. They must report the truth about how they are using and tolerating their medications. If a prescription isn’t doing the job, they cannot adjust it on their own. They need to go back to the HCP, work with their practitioner to address medication issues and, if necessary, have unused medications properly destroyed,” she said.

People with pain who are currently getting good results from ER/LA opioid analgesics should continue to take their medications as directed by their HCP. Health care professionals may require tests and other precautions to control for medication misuse and to avoid overdose.

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According to Dr. Feinberg, opioids can continue to be recommended when other methods have failed and when their use results in less pain, more function, and manageable side-effects. However, it remains important to evaluate each person individually to ensure effective treatment with opioids, and this decision must be a personal one, between people with pain and their HCP.

**Education Keeps Health Care Providers Legally Secure**

“HCPs need to keep current with the FDA and licensing board recommendations for prescribing medications. They are in the business of caring for people and they need be aware of regulatory changes impacting prescribing practices,” Bolen said. “This will also protect them if there is ever a licensing board question or legal challenge against them,” she said. “Good HCPs face these challenges every day. They are not running pill mills; they are good practitioners who have not kept up with the research on medications they prescribe.”

“We need to seek a balance between minimizing abuse/diversion and ensuring access to medication,” Bolen said. “HCPs must evaluate the whole patient, his or her background, health history, and addictive tendencies, but there is also a burden that the consumer bears.”

**Clear Guides for People with Pain**

Pharmaceutical companies will periodically assess how well the educational programs are meeting their goals. The FDA will review these assessments and may require additional elements to achieve the objectives.

“The REMS requires documents that will be easy for patients to read and learn,” said Bolen. Bolen and her colleague, Ted Jones, PhD, who runs a non-profit entity called the Pain Education Institute, in Knoxville, Tennessee, are working on improving relationships between practitioners and their patients through a series of new educational tools.

“When the government has to intervene, it’s clear that something is wrong. REMS is not a criticism of the whole pharmaceutical industry, but indicates that they have a responsibility to improve the situation if they can,” she said. “The industry should be working together to solve this.”

“REMS is a way to fashion new tools and educational materials to help many people. The FDA blueprint is something state licensing boards can use to improve existing pain policies and rules. Licensing boards and HCPs would be foolhardy to resist a chance for better education,” said Bolen.

You can read more about medication safety and REMS in past issues of The Chronicle at www.theacpa.org/Chronicle-Archives.

- REMS: June 2010
- Myths about Medication: March 2009
- Drug Disposal: June 2009
- Avoiding Drug Interactions: September 2009
- Prescription Medicine Abuse: December 2010

**Footnotes and Resources**

1 Statistics and reports on drug abuse from the Substance Abuse and Mental Health Services Administration at www.samhsa.gov/data/
2 www.fda.gov/drugs/drugsafety/informationbydrugclass/ucm163647.htm for specifics about the opioid REMS
5 The Office of National Drug Control Policy (ONDCP) and the National Institute on Drug Abuse (NIDA) www.drugabuse.gov/nidamed/etools
Don’t Let Flare-ups be a Pain

by Sandy Rozelman

I have fibromyalgia. For me, flare-ups used to come on suddenly and could last for days or even weeks. After many of these incidents I realized that a flare-up was just my body telling me something. I just needed to listen.

Before, when a flare-up would hit me, I would, of course, complain and moan and lay around and complain some more. And the more I would lie around, the more awful I would feel. Round and round it went.

This changed when I began to listen to my body. When pain begins to flare up, I listen. What is my body telling me?

Perhaps it is signaling that I need to watch my nutrition. Have I been eating the wrong foods? Too much sugar lately? Too much fast food and sweets? Not enough fresh fruits and veggies?

It could be related to the rest of my lifestyle. Have I been getting enough sleep? Restful sleep? Am I getting enough exercise? Maybe I need to move more. Perhaps my body is telling me to stretch my muscles. They’re getting stiff and sore and achy.

If I am letting too many things and too many people stress me out I need to relax and meditate. It could be time to just breathe, get outside in nature, and see the beauty around me.

Reclaiming My Power
This is what I do now when I feel a flare-up coming on. I don’t just sit around and complain about it. Instead, I focus on reclaiming my power. I no longer let my pain control me. I can control and manage my pain and I believe others can do this as well.

Reclaiming your power means taking responsibility for your pain. No one is forcing you to give in to it, and you can take steps to relieve it.

More and more evidence is coming out that pain is “all in your head.” This is not to imply that our pain is not real, but that it is in our brains.

The pain we feel is not coming from our back or any other body part, but is being transmitted through the nerves to our brain, which in turn translates it into pain.

Because these pain messages are coming from our brain, they should be thoughts we can control through a conscious effort. With practice, I and members of my support group have learned to control our thoughts and reverse the severity of our pain.

I do it every day, every single day. I reply to the pain messages from my brain that are saying “Oh my aching back” by saying “No. I don’t have time for this. You can go away now. I have other things to do and you are not going to get in my way.”

I listen to my body, but I don’t let it control my life. In this way, I reclaim my power over my body and my pain.

Sandy Rozelman is a wellness & lifestyle coach, and facilitator for a wellness support group in Cleveland, Ohio. She is also an author, a wife, mother of three, grandmother of four, at the beck and call to one dog and two cats, friend, collector of frogs, maker of chocolate candy, knitter for charity, volunteer, puzzle and game lover, poet, singer, retired, and 64 years young.
Chronic Pain Teaches Us How to Live a Full Life

by Erin Hart

For the 100 million Americans living with chronic pain, it’s easy to feel overwhelmed. Simple activities that most people do without a second thought, such as going to the grocery store or visiting with grandchildren, can be laborious. Life plans, such as working until retirement age and traveling the world, are placed on the backburner. But as with any condition or life experience, how individuals live this “new normal” is entirely up to them.

Two ACPA facilitators have chosen to use their lives to help others and find new and positive ways of doing all the activities they’ve always loved.

Youthful Energy Powerful Against Pain
Rita-Marie Geary, Rochester, New York, is no stranger to chronic pain. Starting at age 3, she began experiencing near-constant earaches—one that was so severe she had to sleep with her bed angled in the corner of her bedroom so that she could use the connecting walls to prop herself up with pillows.

As she neared her teenage years, the earaches began to fade. Soon after, severe abdominal pain would find her doubled over without warning. Although Geary’s mom had taken her to the doctor early on to have the pain investigated, it wasn’t until Geary was 29 years old that she learned via laparoscopic surgery that she had endometriosis. The condition, which occurs when cells from the uterine lining grow outside of uterus—causing pain, bleeding, and infertility—was something her mom and the treating physician had known, but had never shared with her, all those years ago.

Although living with sometimes-debilitating pain at any age is a struggle, Geary, now 55, says her eager attitude and youth were a great benefit in learning to manage her pain.

“I learned a lot of coping mechanisms when I was young, such as self-hypnosis, distractions, hobbies, prayer, and warm compresses, that continue to help me today,” Geary said. “My youth had me determined and excited to do things and that pulled me through a lot of rough times. I figured out a way to adapt and live without being defined and controlled by my chronic pain.”

Forging a Busy Life
Over the years, Geary dabbled with photography, a hobby that started in childhood. She also enrolled in classes, first at Monroe Community College (graduating in May 1990) and then at the University of Buffalo (UB). Although she had to withdraw from her UB studies to have a hysterectomy at age 36, the operation gave her something that all pain sufferers dream of: a pain-free life. That was short-lived, however, when arthritis and fibromyalgia arrived. Thankfully, these conditions were diagnosed in the early stages.

“Even though I have learned how to cope with the pain, I don’t think I had the quality of life that I have now,” Geary said. “Not only do I have better doctors, but we work together as a team. They value the fact that I’m knowledgeable about my lifelong pain; they value me as a person and what I bring to the doctor-patient relationship.”

Her approach to her pain management has not only benefited her medical treatment, but it has also enhanced her observational and people skills. This has served Geary well as a facilitator for ACPA’s Rochester support group, which she began leading in 2011.

Although most group meetings are small gatherings, Geary is committed to exploring topics and hosting workshops that appeal to a wide variety of chronic pain sufferers—with the hopes of drawing more outside participation. She also encourages other group members to get involved with topic/speaker planning sessions, which has helped the members bond and become friends. Many monthly topics evolve from group members’ individual approaches to pain management, such as music, water therapy, or gardening.

Geary is also looking to mesh her facilitator and mentoring skills to help homebound individuals live better lives with their chronic pain. In 2003 and 2004 while volunteering with the Mental Health Association in Rochester, she met people who

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suffered from mental and physical issues. She believes her personal journey and realizations can help other people stay positive and explore avenues that will enable them, she says, “to live a full and authentic life.”

_Cultivating Personal Interests_

When she’s not helping others, Geary is exploring her own interests. She recently expanded her passion for photography into a small business. She has become very involved in her church—especially with Bible study and overseeing one of the church gardens. Not only is she helping to beautify the church grounds, she is also taking advantage of soil’s natural healing properties to help ease her aches and pain. And when money and time permit, she cultivates her own personal garden on her apartment balcony.

Another bucket list to-do for Geary is learning to play the piano. She finds that music has immediate calming effects on her body. She found this to be especially true after her father’s leg amputation in 2002. Part of his healing involved music therapy, which helped calm and relax him. As she sat with him during these music sessions, Geary says she also felt more realigned and invigorated.

For as many positives as Geary’s pain journey has uncovered, it has also come with the challenging realization that sometimes she has to let the pain guide her day. Her friends, she said, have become sensitive barometers who encourage her to slow down and be mindful of what her body is telling her to do or not do.

Mostly, though, she has learned to seize the good moments and use her life experiences to help others.

“My previous attitude toward people who would say they were in a lot of pain was ‘they should just get over it.’ Never did I realize how physically, emotionally, and financially devastating chronic pain can be until I experienced it. Now I understand,” Cartwright said.

Still feeling the effects of those initial falls, Cartwright, 59, also suffers from carpal tunnel syndrome, arthritis, and fibromyalgia. The pain has put quite a damper on much of her life. The weekly Sunday dinners that she, her family members, and friends treasured are now sporadic. She has trouble bending down and reaching far above her head. Travel is grueling because she can’t sit for long periods of time.

She admits she used to feel sorry for herself. But her attitude and her approach to her pain changed when she lost a dear friend in 2007 as a result of complications from three back surgeries.

“I had been thinking for a while about starting a support group, and had spent considerable time on ACPA’s website researching pain conditions. My friend who had the back surgeries moved to Oklahoma, but was feeling so lonely and isolated because she didn’t have a support system to help deal with her pain. Then she passed. She was my first friend to die in my age group—and the first to pass because of chronic pain. Her death motivated me to move forward and start a group so that I receive support and help others,” she said.

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Helping People Through Their Chronic Pain Journeys

Later in 2007, through the ACPA, Cartwright started a now-monthly chronic pain support group in her local community. The gathering, which started out with five individuals, is run by Cartwright and co-facilitator Sandi Stacy. They guide participants on how to advocate for themselves, remind them of their basic human rights within society and the medical community, and share how to take back their lives from chronic pain—in essence, migrate away from a victim mentality.

“I always share with the group the ACPA’s pain management outlook, which includes doing ACPA assignments, and using ACPA communication tools and other materials. This enables them to determine how they might apply them to their own situations,” she said. “I always have to remind myself, though, that not everyone is in the same place that I am now. We all learn from each other. But the best gift is watching new members emerge from a cocoon, much like a butterfly. They gain their wings and learn how to move forward and how to live the best lives they can despite their chronic pain.”

Although her involvement with ACPA and her support group has done wonders for her pain and her outlook on life, it has also been challenging. It is sometimes hard to engage group members to take on responsibilities for lining up speakers, leading outreach activities, or promoting the group. But as trust among group members builds, so does participation. Cartwright and her co-facilitator work hard to maintain interest in the group by bringing in speakers, having group/social outings, and other fun activities, such as a Christmas gift exchange.

Living Life Mindfully

For as much energy as Cartwright puts into the group, she is also mindful that she must take care of herself and do things she enjoys to maintain balance. She is involved with her church, loves to collect and listen to music, and see movies and theatrical plays. She enjoys meditation and inspirational readings. And although she can’t dance much anymore, she loves attending concerts and taking advantage of the music’s healing and calming properties. Cartwright is also hoping to become involved with more chronic pain advocacy to broaden awareness—both to help people through their chronic pain journey and gain support in the political arena.

With the positive momentum and outlook Cartwright has gained, she realizes that there are times when she has to take a step back and give in to the pain for a day or two. And she’s OK with that.

“This is a mind-body-spirit journey,” Cartwright said. “There are days when they aren’t working together, and it’s OK. I have to be flexible. If my spirit and mind can override the body pain, then I do OK. And what I can’t get done today, I redistribute throughout the rest of the week.”

“Through my connection with ACPA, I have learned to look at what I can do, not what I can’t do,” she said. “And when something new comes up with pain, or I’m having a bad day, I learn how to incorporate that into my life. I have learned to manage my pain, and when something changes, I just go back to the drawing board.”

For both of these women, a big part of continuing to live their new normal includes maintaining a positive mind-body connection and accepting the limitations that chronic pain brings. And when a day doesn’t turn out as planned? There is, according to Geary and Cartwright, “always tomorrow.”
S
ince medical situations can escalate quickly, it is vital
that you advocate for yourself as much as possible. If you
become overwhelmed with this process, you can consult
with a professional advocate who has expertise in navigating
the health care system. Many nurse patient advocates have
practical solutions to multifaceted health problems and can
expedite problem-solving with health care specialists.

Getting the Treatment You Need
Getting the care you need starts with asking the right questions
as they relate to your condition and being prepared for your
doctor’s appointments.

Before Your Appointment
Compile and update your personal medical record and
medication list. Prepare your questions ahead of time to
ensure a focused discussion. Using ACPA communication
tools to track your pain and progress will help your physician
understand your health and pain levels.

During Your Appointment
Provide information about your symptoms and your responses
to medication. Again, the ACPA tools can help. Repeat back
information you are given to make sure you understand what
your doctor is telling you. You or your advocate should take
notes that will help you understand his or her explanations.
You can request websites or written instructions to enhance
your understanding.

Hearing test results or learning that you need surgery can be
disconcerting and frightening. A friend, relative, or advocate
can ask questions if you are emotionally overwhelmed.

Getting More Details
You do have the right to request more detailed information
from your physician. It is often easier to go from simple to
more detailed questions. If you have been informed that you
have a specific medical condition you can ask what your
diagnosis is and request any reading materials about your
condition. More in-depth explanations arise when the subject
of treatments, procedures, tests, and surgery arise. Consider
asking these questions about your treatment options:

- What are these tests for?
- When will you know the results and how will I be informed?
- Are there any risks/complications to these tests or
  procedures?
- What are my treatment options?
- How many of these procedures/surgeries do you perform
each year?
- How soon do I need to make a decision about this
  procedure/treatment?

What could happen if I decide not to have this procedure?
What is the possible prognosis for my medical condition?

After Your Appointment
Review new medication instructions with your pharmacist or
physician. If your symptoms or side effects worsen or if you
don’t understand any instructions, contact your physician for
clarification.

How to Get More Time with Your Physician
The best method is to call the office and ask what is the
best day or time to meet with the physician to have a longer
appointment and be able to discuss your issues in depth.
If they respond with “the doctor spends the same time with
everyone,” tell them in a brief sentence the reasons why you
need more time.

You can maintain your confidentiality by stating that you need
some extra time to discuss surgery, a change or problem with a
medication, the results of a medical test, or whatever issue you
may have. You could also say you are having a bothersome
symptom that requires spending a few more minutes with your
doctor on this visit. If you don’t get anywhere with the front
office, ask to speak to the office manager, medical assistant, or
directly to the doctor. You might also be able to contact the
doctor via email and ask for a longer appointment time.

Disagreements with your Doctor
When you find yourself in a position where you disagree with
your doctor about your treatment plan, or want to pursue
alternative therapies, approach the situation diplomatically.
Tell your physicians that you really appreciate their advice and
recommendations and that you would like to get their feedback
on some other treatment options you have researched.

- Quote articles by reliable sources such as The Mayo Clinic or
  the National Institute of Health to show the physician that
  you are not just accepting any information on the web.
- Don’t raise your voice. Speak in a calm manner.
- Try using open-ended questions so you don’t get just “yes”
or “no” for an answer.

- Bring an advocate along with you. During my 25 years as an
  advocate, I have rarely witnessed a physician getting angry or
  rude with a patient. Interesting enough, when someone else
  is in the room physicians tend to spend more time answer-
  ing questions and may be more polite.

Thinking About Changing Doctors
There are many reasons to consider changing physicians. If you have a feeling that another physician would show
more interest in your medical condition and will be a
better communicator, it could be time to consider a change.
A n animal lover all of her life, Teresa Benton had been focused on trying to nurse her beloved cat back to health after a prolonged illness. It was 2000 when the cat passed away—leaving her to grieve the emptiness her “baby” had left behind. The loss placed her into an unfamiliar world of extreme depression and chronic body pain—the latter, she assumed, a component of the depression.

Eventually, she emerged from the depression and the grief, but the body pain lingered in her hips, joints, wrists, below her neck, and in her knees—essentially, in any movable body part. Although some days were worse than others, she didn’t give the pain another thought until 2003 during a family vacation to Las Vegas with her daughters Brielle and Crista and husband John.

“A few nights before we left, my neck became stiff, but I assumed I was just sleeping wrong—on top of the stress from getting everyone ready to go,” Benton said. “When I boarded the plane my neck felt locked up. Once we got to Vegas, I spent the majority of the time in the hotel room while my family went sightseeing because I was in such extreme pain. And when I did go out, I had to stop and rest often because I felt fatigue and pain.”

Upon her return, she visited her primary care doctor, who ultimately referred her to a rheumatologist. After six months of negative imaging tests and blood work, Benton finally had a diagnosis: fibromyalgia.

“I originally thought it might be some type of arthritis—perhaps rheumatoid arthritis—but I was confused because I thought I was too young for it,” Benton said. “It was such a relief to finally get a diagnosis, because now I had some closure about what I had been experiencing.”

This condition requires you to change your whole way of life

“With a combination of medication and other strategies, the pain can be managed, but not entirely erased. And a medication regimen must be developed for each individual. Benton’s doctor immediately began trying various anti-inflammatories, without success. The next step was steroid injections into her joints—a cocktail that combined anesthetics, anti-inflammatories, and other pain medicine. Although she would feel relief within four to six hours—and much more within 24 hours—it was only a temporary solution that at best lasted a month.

Benton’s doctor then prescribed prednisone, a corticosteroid that finally gave her measurable relief.

“Within six months of steadily increasing the prednisone dose, I had fewer full-blown (pain) outbreaks,” Benton said. “Before taking prednisone, I was in pain 95 percent of the time. Although I wake up every day with some grade of pain, I now have only one day a week where I am in full outbreak mode.”

A Wide-Spread Chronic Pain Condition

Fibromyalgia affects from 2 to 4 percent of the population, between 6 to 12 million Americans, with an estimated 70 percent undiagnosed. Roughly one in 30 women experience fibromyalgia, while only one in 200 men develop it.

Although fibromyalgia is not life threatening, it can be debilitating in the affected person’s daily life and is marked by chronic, widespread pain and tenderness, decreased physical function, fatigue, and difficulty sleeping.

With this doctor’s approval, Benton created her own homeopathic treatment. She began taking vitamins, started practicing...
yoga, enrolled in water therapy classes, and changed her diet. She also tried myofascial massage and acupuncture but was unable to continue the latter because of the expense.

"Although exercise is recommended for patients with fibromyalgia, it hurts to do this because of the pain. When I started yoga, though, my mental temperament and attitude changed for the better. I started a Mediterranean diet, which is basically beans, fresh vegetables, fruits, nuts, Greek yogurt, and olive oil. I stopped consuming white enriched flours, caffeine, sugars, and salt. My diet is now focused on plant-based foods—if it comes from the ground, I eat it. When grocery shopping, I stick to the outer perimeter of the store and stay away from the middle aisles," she said.

With the lifestyle and dietary changes, and continued use of prednisone, Benton, now 48 years old and living in Riverview, Florida, has experienced measurable success. Initially prescribed 12 mg. of prednisone, she is now down to 4 mg. per day. If she has successive good days, then she is allowed to skip the medication. However, it’s only a matter of time before the pain creeps in again.

**Listening to One’s Body**

Fibromyalgia has taught Benton to understand her pain triggers, physically and mentally. Yard work or other physical activity is limited to 45 minutes or less. She makes sure she gets eight to nine hours of sleep per night and manages her daily activities to avoid what she terms “a bad mental day.”

Having this condition has forced her and her loved ones to live differently, and not all in good ways, Benton said.

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Part Two: How to be Your Own Health Advocate

CONTINUED FROM PAGE 9...

It might be wise to choose another physician if:

✶ Your phone calls are not returned from your physician in a timely manner.
✶ Your questions are not welcome.
✶ The physician is always rushed, spending less time and concentration on your questions and concerns.
✶ You have a chronic condition, and your physician is not familiar with your medical condition. During your medical visit, if your physician appears to be unfamiliar with your condition, can’t recall important information from your last visit (even with detailed notes), and you need to repeat the same information on each visit, it might be time to switch doctors.
✶ Your doctor is harsh, unsympathetic, or shows no interest in your condition.

The House That Jack Built

CONTINUED FROM PAGE 1...

You see, they had both worked very hard all their lives. Their children were now at an age where they could help out around the house and did not need supervision as they had when they were younger. This was to be the house that would provide each of them a sense of pride, of working hard for their dreams. So each member of the family took responsibility for helping Jack with the details of finishing the inside.

The last stage of the house came in June when they all helped to landscape the yard. This was the highlight of the building process. The entire family really enjoyed the outdoors and it was a bonus when they could work together outside while finishing the house. The yard was seeded and the flowers set around the house and driveway. The family even planted a vegetable garden in the backyard, from which they would reap a harvest during the late summer and fall.

They moved their furniture into the house that Jack built by July 4. What an event! What a way to spend their Independence Day! The house that Jack built—with the help and support of his family—was a monument to his determination and belief that anything is possible.

You see, Jack was working under what some would consider a handicap. Many years earlier, Jack had experienced a stroke, leaving him with impaired speech and only partial use of his left arm. In spite of the odds and with the help of his family, he was able to build the house of his dreams.

How was this possible? He believed in his ability. He had learned that if he focused on what he could do, there was little time for him to think about what he could not do.

✶ When something came along that required help, he asked for it. He knew he had the right to ask for help.
✶ When he felt like he was pushing himself too hard, he would stop. He knew he had the right to do less than humanly possible.
✶ When he made a mistake, he did not tell himself that he had no right to be building a house in his condition; he knew he had the right to make mistakes.

Wouldn’t it be nice to have a positive attitude like Jack’s? It is possible. All you have to do is believe in yourself and in your abilities while using your basic rights each day. With a real belief in your abilities, you too can build a house with a strong foundation to hold your life firmly in place. We all need a house that is strong and will provide us with comfort and a sense of well-being. You are the architect of your life. Make sure that you build your house on a solid foundation and know that anything is possible.

The ACPA basic rights are your foundation for a better way of life. Read them over each morning before you start your day. Your basic rights validate you as a person equal to everyone with whom you share your life.

You can find the ACPA’s list of Your Basic Rights at www.theacpa.org/Your-Basic-Rights.

When looking for a new physician, it is frequently helpful to do a “yelp” search online to see what other people are saying and experiencing with a particular doctor.

Any choice for a new physician should be one who is covered by your insurance and is accepting new patients. Find out how you can transfer your medical records to a new health practitioner. Records can be faxed or mailed to your new physician or you could request to take your medical records with you and hand deliver them. It is important to make an appointment with your new physician as soon as possible so you will have established your relationship before a major health problem or emergency occurs.

To read part one of this series, go to the December 2012 issue of the ACPA Chronicle, page 12.

Linda Garvin is a Nurse Health Advocate with 30+ years of experience. She will help explore which health care options are right for you. She is the founder of Patient Advocate Bay Area, Inc. in Alameda, California and works with individuals across the country. Learn more at www.patientadvocatebayarea.com or e-mail info@patientadvocatebayarea.com.

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ACPA Updates

Website Wins eHealthcare Leadership Award
The ACPA website, www.theacpa.org, has been recognized for providing readers with quality information to improve their health and well-being.

The website, designed by the ACPA and New Perspective of Pittsburgh, Pennsylvania, (www.new-perspective.com) received an award of Distinction in the Best Healthcare Content category of the 2012 eHealthcare Leadership Awards. ACPA was one of 240 healthcare organizations that received recognition for its outstanding websites and digital communications in November 2012.

Veterans In Pain Events 2013
During 2013, Veterans in Pain will hold events around the country. Join the community section of the www.vetsinpain.org/ to stay up to date.

❋ March 21, Salt Lake City, Utah
❋ April 25, Danville, Illinois
❋ April 26, Indianapolis, Indiana
❋ May 16, Sioux Falls, South Dakota
❋ May 23, Columbia, Missouri
❋ June 4, Butler, Pennsylvania
❋ June 27, Portland, Oregon
❋ August TBD, Grand Island, Nebraska
❋ October 2, New York, New York

Double Check, Don’t Double Your Dose
During spring allergy season remember to Check Your Dose to be sure that the over-the-counter medications you take don’t double up on medicines containing acetaminophen. Acetaminophen is the most common drug ingredient in America, found in more than 600 over-the-counter and prescription medicines, including many for allergies, cough, cold, and flu.

Acetaminophen is safe and effective when used as directed, but taking more than directed is an overdose and can lead to liver damage.

❋ Check if your medicine contains acetaminophen.
❋ Never take two medicines that contain acetaminophen at the same time.
❋ Always read and follow the medicine label.
❋ Ask a healthcare provider or pharmacist if you have questions about dosing instructions or medicines containing acetaminophen.


Guiding Web Users through the Maze of Pain
The ACPA website is a primary resource for people with chronic pain trying to improve their quality of life, and for the professionals who help them. But sometimes, learning to live with pain can feel like wandering through an endless maze, going from one dead end to another as you search for answers.

A new tool on the ACPA website helps you navigate the maze of pain, one turn at a time. The guide through the Maze of Pain allows you to narrow down your search to more quickly find the information you need. Directed to the topic of your choice, you will find communication tools sorted by use and videos that relate directly to your concerns.


The Maze of Pain is supported by funding from Horizon Pharma, Pfizer, and Purdue.

The award-winning ACPA website – www.theacpa.org
Thank You!

Since 1980, the American Chronic Pain Association has provided people who must live with daily pain a means to help themselves to a richer, fuller life. We are grateful to have the support of these corporate sponsors for our mission:

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Medtronic  
Purdue

**BUILDER**  
Abbott  
Horizon Pharma  
Pfizer  
Zogenix

Honors for the ACPA’s Penney Cowan

Penney Cowan, founder and chief executive officer of the ACPA, has been recognized for her work by two leading organizations in the pain field.

She will receive the American Pain Society (APS) 2013 Elizabeth Narcessian Award for Outstanding Educational Achievements in the field of pain in May 2013, during the society’s annual scientific meeting. In 2005, Penney also won the John and Emma Bonica Public Service Award from APS.

In addition, the American Academy of Pain Medicine will award Penney a Presidential Commendation in recognition of her “commitment to being an active voice supporting the needs of all people who suffer with chronic pain.” It will be presented at the group’s annual meeting in April 2013.

Anyone who has worked with Penney over the last 30-plus years knows that this recognition is very well-deserved. It is gratifying to see that our work, with all your support, has clearly made a difference in the world of pain medicine.

Congratulations, Penney!

Tributes

**IN MEMORY OF**  
Mary L. Shumate

Given by  
Marie Heinz

The ACPA is a peer support organization: we help each other learn to live fully in spite of chronic pain. Your membership, donations, and purchase of materials keep the ACPA alive and reaching out to even more people with pain.