When was the last time you asked your healthcare professional (HCP) this question?

“I don’t understand what you just said. Can you please tell me in terms that I will understand?”

Communication is essential in following instructions—for assembling a bookcase, finding your way to the bookstore, or using the right ingredients for a recipe. It is most important to comply with your HCP’s instructions, yet too often, there are disconnects between the person with pain and the provider.

Communication is the thread that binds the person with pain to his or her HCP. We know that people with pain want their pain validated, especially by their HCP. Yet we lack the right words to describe our pain and the impact it has on our lives.

For good or bad, when we look at most of the people who live with pain; the first impression is that they look “normal,” just like anyone else.

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Effective Communication Empowers Those Living With Chronic Pain

by Erin Hart

For each of us, communication skills are ever-evolving. They involve give and take, careful consideration of others, and years, if not a lifetime, to perfect.

For the two women profiled here, good communication has been key to interacting more effectively with others and finding their purpose as they navigate their lives with chronic pain.

Commanding Respect

If there’s one thing that Karen Davies, 70, of Ampelone, California, has learned in the last 14 years of living with chronic pain, it’s that communicating openly and honestly about her condition—without dwelling on it—has earned her the respect she deserves.

After experiencing increasing perineal hip pain in 2000, Davies received word from her orthopedist that she needed both hips replaced. Thinking this would solve her pain issues, Davies agreed to one replacement. However, the pain remained. After undergoing additional tests, a specialist found a cyst on the bottom of her spinal cord, Davies said. Later a neurologist determined it was a Tarlov cyst (a fluid-filled sac that most often affects nerve roots at the lower end of the spine). Although doctors made several attempts to drain the cyst, Davies said the pain persists—and likely will for the remainder of her life.

She didn’t feel comfortable talking with colleagues in the early years of her pain journey. But Davies said she has learned through her involvement with the ACPA—and by employing its various tools—the importance of being open about her condition and specific needs. The result, she said, has been better care from healthcare providers, and more understanding and care from family and friends.

“I’ve always been one who states things as they are,” Davies said. “And my approach hasn’t been any different throughout my chronic pain journey. With my doctors, I say ‘what is.’ And if I don’t like the answer I get, or sense they aren’t really listening to me, I find someone who will listen.

“With family and friends, I’ve been honest in telling them that there is nothing they can do to help my pain—other than being understanding when I can’t accept an invitation, or helping out when I can’t do things. I also requested that they not be continually asking about how I feel because I don’t like to dwell on the pain. And they have truly been supportive.”

Empowering Others

For the last six months, Davies has led the Roseville, California, ACPA pain support group. She enjoys interacting with others, learning about their challenges, and helping them become better advocates for themselves with friends, family, and healthcare professionals.

“For some individuals, this group is the only outlet of personal support they have, so I encourage them to be open and share—because it truly does help. And I think that learning to be open with friends and family empowers them to communicate well with healthcare providers, which is extremely important when it comes to managing their pain effectively,” she said.

Be Upfront and Enjoy Life

Here is one piece of advice Davies shares with her group members. Although it is important to take care of themselves first, they should continue doing the things they love to do. And if they can’t keep up with others? Then be open about it.

“In September, I flew to Europe for a three-week history tour, which I absolutely enjoyed,” Davies said. “I explained to the group and the guides at the beginning that I have chronic pain, and that I may not be able to do all of the activities or keep up with everyone. And they were very appreciative of my honesty, and respectful of my limitations. And I still had a lot of fun.

“One of the things that I’ve learned about living with chronic pain is that my pain is the same, whether I’m home or if I’m out. So I may as well get out and enjoy life while I can.”

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“One of the things that I’ve learned about living with chronic pain is that my pain is the same, whether I’m home or if I’m out. So I may as well get out and enjoy life while I can.”

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Pain Taught Her How to Ask for Help
More than 18 years ago, Susan Spadone was a Type A workaholic—one who hated to wait for things, especially if that meant asking for help.

Then at work one day, this non-communicative approach changed her life. While lifting boxes, she injured her lower back to the extent that she was no longer able to work. And she was told that surgery was the only way to “fix” the injury.

Instead of questioning the diagnosis, Spadone, 56, of Mountainside, New Jersey, went along with the recommendation, not thinking of long-term implications. However, lying in recovery, Spadone knew something hadn’t gone well. Her pain levels had increased. She underwent a second surgery 10 months later, and was again flattened by yet another unsuccessful procedure.

“I was in pain 24/7, and absolutely nothing helped,” Spadone said. “I was in this years-long bad cycle of feeling helpless, hopeless, isolated, and depressed. I wasn’t working; I was out of shape, and people were disappearing from my life. I didn’t like myself, so why should they like me?”

A Turning Point: Finding a New Life
Twelve years passed. One afternoon as she watched TV, a mainstay of her life in those days, she became fixated on a show about women who were trying to start a new life. And it got her thinking about her own life, how her current situation was unsuitable, and how much she had to offer others going through similar situations.

Spadone enrolled in an outpatient day program that incorporated interdisciplinary methods of medication, physical therapy, occupational therapy, biofeedback, psychotherapy, and aqua therapy. She was hooked, and thriving, and she knew what her next move would be.

After acquiring a certificate in Water Exercise, she began teaching aqua therapy classes. Spadone started to feel hopeful again because she was interacting with others and helping them with the physical aspect of their pain journeys. But she wanted to do more. Drawing on her background in psychology, she enrolled in a life-coaching program and just two years later, became a full-fledged coach.

“This was a major turning point for me. I realized that instead of shutting down and accepting my fate, I needed to open up and use my experience to help others,” she said.

Helping Others Help Themselves
Life coaching is very much about communication—helping others to open up about what they are feeling physically and emotionally. These are tangible stories, Spadone said, and life-coaching helps to give them wings and let them fly. After several sessions (which vary between four and 12 depending on client motivation), many individuals are more open to embracing their pain and the opportunities it can bring. They are also more willing to extend themselves and try activities they may not have attempted before. What results is a more stress-free existence, which means chronic pain is much more manageable.

Spadone incorporates many of these techniques into the ACPA group that she facilitates at the JFK Medical Center in Edison, New Jersey.

“Talking is essential, because to get anything out of our groups, folks have to open up,” Spadone said. “Sometimes it takes extraordinary measures for this to happen, but once people see that you are empathetic and care, and that you aren’t there to judge them, they come out of their shells.”

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Effective Communication Empowers Those Living With Chronic Pain

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Sometimes there are group members who want to come and “report” on their situation. But she tries to guide the discussion in a way that is helpful to all members. She aims for a conversation where everyone feels included, and most importantly, leaves their sessions feeling uplifted.

Evolving Personal Communication Styles

Although communicating professionally has been cathartic for Spadone, her personal communication style, whether with family members or healthcare providers, is always evolving. With healthcare professionals, she has learned to prepare for doctor visits—bringing with her an agenda and handouts of topics she wants to discuss, as well as a positive outlook. With family, Spadone is direct, succinct, and authentic. And if someone can’t quite understand what she’s feeling on a given day, she will describe an example they can relate to. Chronic pain, Spadone explains, is open-ended and never goes away.

Spadone has also relaxed the standards of her old Type A personality. She is more self-aware and isn’t afraid to ask for help. She is also more aware of how others feel, such as her husband Mark. Once, their social activities hinged on the level of Spadone’s chronic pain that day. Now, it is a mutual, equal decision. Spadone always solicits Mark’s input about attending a gathering, which has changed their dynamic in a very positive way.

Regrets and Reflections

As Spadone reflects on her life and choices she’s made, she wishes deeply that she hadn’t undergone the surgeries; that she had been more of an advocate for herself when healthcare providers pushed treatments she wasn’t truly ready to accept. She shares those lessons learned with others who are beginning this journey.

“Be kind to yourself – and be open to new experiences. When a medical professional proposes a procedure, take the time to research and think about it. Be direct and communicate your needs. You know your body – and it’s OK to think about it and come back later.”

“Chronic pain has been a blessing in disguise—putting me in a position to rethink my entire life, ranging from my goals to my relationships. It has changed the way I interact with others—in a good way. If my chronic pain condition hadn’t happened, I wouldn’t have experienced the myriad blessings and gifts I have received. I want to continue using this experience to impact others’ lives in a positive way.”

Source


With healthcare professionals, Spadone has learned to prepare for doctor visits – bringing with her an agenda and handouts of topics she wants to discuss, as well as a positive outlook.
Communications Can Bridge the Gap
CONTINUED FROM PAGE 1...

Pain is invisible and there is no way to see it. This makes it even more difficult for others to believe you have pain.

So how do you make the most of a visit with your HCP? The goal is to leave the office feeling that you had a meaningful conversation and used the opportunity to discuss your pain and related issues in detail. But we all know that time is short during these appointments. Most of us want to describe our symptoms, pain, and limitations in detail. It leaves little time to discuss medications and other recommended treatments.

Tools to Help You Explain
The ACPA has designed tools to help bridge the gap of communication between you and your HCP. These interactive tools, on our web site at www.theacpa.org, can help you explain your pain in different parts of your body. These pain maps create a picture of where your pain is, how it feels, and the intensity.

The ACPA also provides a wealth of other tools to help you explain, using graphics, the impact pain has on your life and everyday tasks. For example, the newest tool uses graphics and an accompanying video to initiate a discussion about opioid-induced constipation.

You can use the ACPA graphic tools to prepare for your next medical visit. They can help ensure that you have meaningful conversations while you are with your HCP. This will help you fully understand your role in the treatment plan.

Here are a few tips to help you communicate well during your visit:

❋ Before your next appointment, write down the questions that have come up since your last visit.
❋ Make notes of what is said during your visit, so you can refer to them later.
❋ If you do not understand what is going on, tell your HCP and ask him or her to explain in terms that you can understand. Remember the only dumb question is the one that you did not ask!
❋ It is a good idea to take someone with you if you have trouble remembering all that takes place during an HCP visit.
❋ Most of all, remember that you are part of the treatment team. If you remain passive and do not make your needs known, they will never be met.

In this issue, we will meet some facilitators who have learned how important it is to communicate with their friends, family, and HCPs. We will review the ACPA communications tools in detail. We will also share some tips on how to improve your communications skills to get the help you need, and assert your rights, to live better with pain.
B eing able to talk about pain is so important in daily life, but it is essential when the conversation is with a doctor, pharmacist, nurse, or therapist.

Consider these two responses to a medical professional who asks, “How have you been feeling with the new medication?”

1. “OK. Some days are better than others. I feel tired and edgy, and my brain feels foggy.”

2. “In the last two weeks, I stayed in bed two days. My pain was less intense on the five days I exercised. It was more intense at night and I slept poorly three nights. I had no appetite for the first two days, but that improved. I dozed off six afternoons around 5 p.m. Twice I couldn’t remember where I was going when I left the house, and I often misplaced my keys.”

It is obvious which response provides more information and may help in managing pain and medications. Providing this level of detail is much easier when you use communication tools from the ACPA.

These tools help you develop a precise, daily record of pain and activity levels. They can help you give your healthcare provider a clear understanding of how your pain and medications are affecting your life. This helps you and your doctor adjust your treatment plan and better control your pain.

ACPA tools can also help you identify your personal pain triggers, patterns in your daily life that have an impact on your pain. When you understand these, you can deal with them proactively.

All the tools described here can be downloaded from http://www.theacpa.org/Communication-Tools. Some can be printed, while others can be completed and saved online. You can also order them in sets of 25 or 50 through the ACPA store, under literature. http://www.theacpa.org/store.aspx.

**Live Better with Pain Logs**
The Live Better with Pain Log is available in English and Spanish. There is also a specialized pain log for those who live with fibromyalgia.

Completed online or on paper, the logs use graphics to let you rate your level of health and activity from one to 10. The chart rates levels of pain, stress, exercise, activity, sleep, medication use, side effects, constipation, fear of pain, sexual activity, appetite, mood, social interaction, alcohol use, and finances. The Fibro Log—specifically for fibromyalgia—includes many of these, along with weight loss or gain, morning stiffness, fatigue, changes in the weather, and ability to concentrate.

The logs are most beneficial when completed each day or several times a week. You also can print a report and take it to your doctor visits.

**Pain Maps Identify the Symptoms**
Because it is impossible for anyone else to feel another person’s pain, words often fail to explain how it feels. Time is short during doctor visits, so these interactive tools help you share information quickly.

The Fibro Pain Map, Nerve Man, and DPN Person (Diabetic Peripheral Neuropathy) let you create a detailed picture of your pain, where it is, how it feels, and how much it hurts. This graphic representation provides a lot of important information in an easy to understand and accurate way. It lets you identify the symptoms associated with different types of pain in different parts of the body.

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Arthritis Ability Chart and Quality of Life Scale

The Ability Chart is helpful for those with arthritis, as it allows you to identify the areas where you struggle with everyday tasks, such as climbing stairs, getting out of a chair, or bathing. There is also a Daily Activity Checklist for those with other types of pain. These tools let you show your healthcare providers which aspects of life are most challenging. Together, you can tailor your treatment plan to meet those needs.

The Quality of Life Scale also measures how well you are functioning, which helps your provider understand how pain impacts your life. The scale starts at level zero: “Stay in bed all day. Feel hopeless and helpless about life.” Quality of life improves through to level five, “Struggle but fulfill daily home responsibilities. No outside activity.” Level 10 is considered a normal quality of life, “Go to work/volunteer each day. Have a social life outside of work. Take an active part in family life.”

Ways to Start a Conversation

To make the most of your time with your doctor, use the Prepare For Your First Visit communication guide. This chart helps those with fibromyalgia summarize their symptoms. You can make notes of how your condition has changed since your last visit, and how medications and other methods of relief have affected your pain in different parts of your body.

Having to live with chronic pain is difficult enough without the added burden of opioid-induced constipation. An ACPA video and conversation guide will help you have a meaningful conversation with your healthcare provider. The Opioid-Induced Constipation Communication Guide allows you to track the opioids you take, and the side effects caused, including abdominal pain and bloating. You can also record your water and fiber intake, appetite, and exercise routines to give your doctor a good understanding of your situation.

Tools for Doctors and Pharmacists

Sometimes it is the healthcare provider who needs to improve communication. If patients understand what is expected of them, they do a better job of complying with instructions.

The Pharmacist Care Card shares simplified, graphic instructions from a pharmacist to the person with pain. It clearly depicts how and when medication should be taken, what things to avoid while taking it, as well as possible side effects.

Similarly, the ACPA Follow Up From Your Visit tool lets healthcare providers create a simple pictorial reminder to ensure that you complete all the treatments, advice, and recommendations from the appointment. It includes restrictions, treatments, follow-up tests, diet, and the date of your next visit.
We know that chronic pain affects not only the person experiencing it, but also those who surround you. Spouses, children, siblings, and parents must learn how to cope as a family with the challenges of living with pain.

Your family can be your biggest ally, especially when you communicate with one another. Unfortunately, all too often, misunderstandings go unchecked. Soon there is no communication.

No one can read our minds. Unless we tell people what we are feeling, they will not know. If we need support, a sympathetic ear, encouragement, or help, we must ask for it. Without this clear communication, actions can be misinterpreted. You may need to speak up to “clear the air.”

When it is not possible for the family to resolve differences, there are professionals who can help. Having the support of your family is worth the effort of making them understand what you need and how they can help.

If you are to continue to grow in your understanding of pain management, you need to communicate to your family, friends, and significant others the important of personal growth, not just yours, but theirs as well. Open communication is the only way to recognize and measure personal growth.

There are many ways that people express themselves. Our feelings are reflected in both our words and actions. Verbalizing how one feels is comfortable for some people. Expressing emotions through actions is another form of communication that others may prefer.

The problem with acting out emotions, rather than verbalizing, is that actions—and therefore emotions—can be misunderstood. Stating just how you feel provides a clearer picture of what you are experiencing.

**Tips to Establish Open Communications**

Establish a time each day that the family is together. It could be dinner time, or breakfast, or a time when you aren’t all going in different directions. Find a time each day that will give you a chance to share the day’s experiences and discuss any problems. If time seems to be at a premium, a chalk or pegboard can become a mood meter. Use stickers or magnets to allow each person to state their feelings that day: happy about a date, upset about school, or nervous about work. Seeing what is happening in each person’s life will foster communications, and encourage questions and discussion.

Ask questions. It can be easier to bring up your problems, and not feel you are complaining, if someone inquires about it. If you think someone is having a bad day, ask them about it. If no one volunteers information and we don’t ask, we can only make assumptions, which could easily be wrong.

**Learn to Ask for Help**

When we are struggling with a difficult issue, it can be very hard to ask someone for emotional support. Perhaps we feel that asking for help further reinforces a sense of weakness. You may struggle to accomplish things you “used to” or “should” be able to do. If there are many things that are now beyond your grasp, you may try to limit the amount of assistance you request, to not be a burden on others.
However, if you were moving a piano, you wouldn’t hesitate to find others to assist. Asking for help merely shows you are aware of your limitations. You have a task to accomplish. If it requires someone’s help to complete it, then ask.

And don’t assume it is apparent to those around you that you are in need of help. Unless you make your needs known, they will not be met.

Sometimes we assume that it is evident to everyone that we are, in fact, struggling. We think that, instinctively, they should be supportive of our efforts. That is not so. They may be very willing to provide support, or lend a hand, but first they must know that we need it. So, we need to learn to ask.

Know When to Say No
Don’t allow yourself to feel guilty when you say no. In addition, don’t feel as if you have to always explain your reasons for saying no. You have the right to choose what you do with your time.

If you feel completely caught up in making everyone else happy, you might feel used and run out of energy very quickly. When you say yes to the activities that are most important to you, people will know that you are doing them because you want to, not because you feel like you have to. Your interaction with others will improve and communications will become more open.

Talking to Children
Children may have the most difficulty coping with a parent or sibling with chronic pain. It is easy for them to misunderstand, or even feel responsible for the pain. If you want to avoid this, you need to tell your children that they did not cause your pain.

You may also want to explain that the pain can make it hard for you to play with them or be very happy. It might make you grouchy or tired. They don’t have to change their behavior, but there will be some days when they may have to be patient with you. Try to let them know when it looks like a day will be difficult one.

If you can, find alternate activities that can be saved for days when you have a lot of pain, or don’t have much energy. Those activities, perhaps reading, listening to stories or music, or doing crafts, can become part of a special time together.

This article was drawn from Staying Well: Advance Pain Management for ACPA Members, by Penney Cowan; ACPA, Copyright 1994; Chapter 4, “Family Needs” and Chapter 8, “Time Management”.

Your family can be your biggest ally
These articles are intended to give members more insight into the interests and contributions of ACPA board members.

Lisa Saake, RN, MSN, MBA, has had two wonderful careers, as a nurse and nurse administrator, and building medical advocacy relationships for a pharmaceutical company. While she contemplates her next move, she is working as the newest member of the ACPA Board of Directors.

Saake, of St. Louis, Missouri, is the former Senior Director of Global Healthcare Policy, Economic Outcomes and Medical Advocacy at Mallinckrodt Pharmaceuticals. During her 18 years there, she conducted healthcare policy research, strategy, and education to help people who benefit from the opioid narcotics that the firm manufactures.

In 2011, she assumed responsibility for a Mallinckrodt initiative called C.A.R.E.S. Alliance. It brought together national medical, patient, advocacy, safety, and anti-drug diversion organizations to focus on responsible prescribing and safe use of opioid pain medications. ACPA was also a member, and it was then that Saake met ACPA executive director Penney Cowan.

“As a nurse, I love tools and I was fascinated by the communications materials that the ACPA has developed. I am attracted to the group’s mission and how we are helping people with pain have a voice in the world,” she said.

“There is a role for drugs in managing acute and chronic pain, but it requires a holistic approach,” said Saake. “The ACPA has great books and guides to help people understand all their options.”

Prior to joining Mallinckrodt, Saake worked for many years as a nursing director at Cardinal Glennon Children’s Hospital in St. Louis. She completed her undergraduate degree in nursing from St. Louis University and earned a Master’s Degree in Nursing Administration from St. Louis University. She also has an M.B.A. from Southern Illinois University at Edwardsville.

“Both of my careers have been very rewarding. In nursing, I made a difference in the lives of children and families. In the for-profit sector, I contributed toward research into how drugs could make a difference in the lives of people with pain. I put my business degree to use and it was intellectually stimulating,” Saake said.

“When I left Mallinckrodt, I reached out to Penney because I wanted to stay connected to advocacy work and maybe participate in some projects for ACPA. She asked if I’d like to join the board,” said Saake.

Saake sees multiple challenges for people with pain and their doctors in today’s medical environment, changes that are challenges for ACPA as well. “If you are seeing a doctor on a regular basis, using ACPA’s paper tools to keep diaries of your health and activity levels is very beneficial. But with the growth in electronic medical records, such as those centralized in medical homes, we must consider how that affects our strategic direction,” she said.

“We have a challenge and opportunity as healthcare evolves in the electronic age. Do we move our tools into electronic formats? How will people with pain communicate with caregivers through telemedicine and virtual office visits?” she said. One area where Saake feels she can contribute is by encouraging research to establish the scientific validity of the ACPA communication tools. “If the medical community embraced these in a mainstream way we could help even more people,” she said. Though she acknowledged that there is tremendous anecdotal feedback that these tools work, she says that tangible measures of success against meaningful objectives would be of immense value in the medical community.

Her retirement, though it may be temporary, has been a wonderful opportunity to spend time with her extended family, travel, and consider what her next career should be. “Meanwhile,” she said, “I’m delighted to be working with the ACPA.”

“As a nurse, I love tools and I was fascinated by the communications materials that the ACPA has developed. I am attracted to the group’s mission and how we are helping people with pain have a voice in the world.”
Pain’s Lessons are Life Lessons

by Carol D. Marsh

None of us would choose our chronic pain. I would get rid of these migraines in a second if given the opportunity. Yet many of us have, through our pain, discovered spiritual learning, a kind of deepening that we might not have come to left to ourselves. There exists an interaction between pain and spirit that is symbiotic: pain informing spirit and spirit informing pain.

My first experience with this symbiosis occurred when I began trying progressive (or deep muscle) relaxation in an effort to cope with migraine pain untouched by medications. The practice, developed in the 1920s by Dr. Edmond Jacobson, uses consciously produced muscle tension, then conscious relaxation of those muscles, to achieve a tension- and stress-reducing relaxed physical state. It often begins with instructions to curl your toes as hard as you can ... hold for a few seconds ... and relax. You then proceed to the feet, calves, thighs, and so on until the entire body is quiet and peaceful.

Practicing progressive relaxation helps me deal with chronic pain by relaxing muscles that are unconsciously tight under the stress of the pain. It changes my biological systems. I breathe more deeply and slowly. My heartbeat seems quieter and slower. Often the release of this stress energy in my body induces tears of relief. These tears seem to be an expression of healing the emotional pain that accompanies chronic pain. The pain of the migraine is still present, but somehow it is now less significant.

Progressive Relaxation and Meditation

When I started this relaxation technique, I had been meditating for a number of years as part of my spiritual practice. I’d always had trouble settling and quieting my mind. I’d long assumed that distraction would remain a major component of my meditation. But during those early trials with progressive relaxation, as I lay on the bed in my darkened room, meditation simply happened in a way that had not been possible for me before.

Amazed, I began paying attention to a positive aspect of living with chronic pain.

I know. Who would put those two phrases—positive aspect and chronic pain—in the same sentence? Yet when I realized this helpful interaction between pain management practice and spiritual practice, I was at a point where I was tired of complaining, tired of wishing my life were different. I was tired of getting upset so often about having to stay home in a dark, quiet room rather than meet my friends for lunch or go to the party I’d been looking forward to. Tired of being tired of. The realization came when I was ready for it to come.

Accepting the Inevitable

It’s a choice, isn’t it? I can choose to allow the restrictions on my life to upset me and make me tense, stressed, and depressed. Or I can choose to accept the inevitable—pain—and then embrace the positive—emotional and spiritual growth. Acceptance, of course, comes first. There is no finding the positive in pain until its presence is accepted.

That unexpected doorway to meditation that I found in deep relaxation practice was serendipitous. I was lucky that it happened, and that it happened when I was already taking a look at my life and becoming unsatisfied with how I handled living with chronic pain.

Since I began to explore this interaction between my spirit/emotion and pain, I have learned some very helpful things.

❋ Simply accepting that pain is part of my life reduces stress and tension, thereby eliminating emotions that only make pain worse.
❋ Accepting pain rather than fighting it opens my heart and spirit to allow learning and growth.
❋ An open heart and spirit spill over into other aspects of my life and carve out a place for peace and joy within me.
❋ These lessons learned from pain are life lessons.
Running for the ACPA
Amanda M. Ryan, 25, raised more than $2,135 for the ACPA through her participation in the Chicago Marathon on October 12. This is her second fundraising run. In 2013, she completed her first half marathon, and her contributions to the ACPA totaled $1,193.

“This year, I’m running my first full marathon in Chicago in honor of my sister, Adrien. Running a marathon has been a big goal for me for quite some time, and I thought this would be a perfect opportunity to fundraise for ACPA once more,” Amanda said.

Adrien, who has fibromyalgia, just began her sophomore year at D’Youville College in Buffalo, New York. “She’s made great strides academically thus far and is at the top of her class. Although her diagnosis of fibromyalgia has been discouraging in the past, she continues on and keeps achieving so much,” Amanda said. Amanda participates in the marathon as an employee of Bank of America Merrill Lynch in Boston, Massachusetts.

“I ran the Chicago Half Marathon last year and am so excited to travel back in October to double my mileage,” she said. Her fundraising page is http://www.firstgiving.com/fundraiser/amandaryan2/2014chicagomarathon.

Board of Directors Review 2014
The ACPA Board of Directors met in October 2014 to review accomplishments and plan for the year ahead. Board President Donna Kalauokalani, MD, MPH, welcomed the three newest board members, Chris Duncan, Keyola Panza, and Lisa Saake.

In 2014, ACPA stayed true to its three-part mission: educating people with pain, caregivers, and healthcare providers (HCPs); spreading awareness; and enabling 225 ACPA peer support groups nationwide.

ACPA continues to update our publications and videos. These include resource guides, audio programs, the Coping Calendar, and tools for families, HCPs, and pharmacists. Some of this year’s topics are understanding medical devices, using NSAIDs, opioid-induced constipation, and opioid safety. In 2014, Executive Director Penney Cowan (and other board members) made presentations at medical conferences and to many gatherings of people with pain.

Those included 18 Vets in Pain programs in 2014, attracting hundreds of people in cities across the United States including San Juan, Puerto Rico. We now have 105 support groups for veterans.

Other initiatives in 2014 were:

* More interactive features to attract youngsters to the ACPA’s Growing Pains website, where they can share their feelings, gain validation, and learn pain coping skills.
* The Art of Pain Management, which provides relaxation through music composed by R.G. Farrell especially for the ACPA
* Sponsorship and participation in the Pain Matters documentary on the Discovery Channel
* Helping to launch the International Network for Understanding Pain in Europe.

In the next issue of the Chronicle, we will highlight some of the activities planned for next year and beyond.

Pain’s Lessons are Life’s Lessons
CONTINUED FROM PAGE 11...

I hope this doesn’t sound preachy. I ascribe to no particular religion or spirituality. The body-mind-spirit connection of pain management strategies just happened. I have no degree; I’ve conducted no formal study. I have only my own experience of the journey toward the ability to live well with pain. I am grateful for it.

And I’d still give up this migraine pain in a heartbeat if I could.

Carol D. Marsh, is a writer and blogger living in Washington, DC. She has recently published a story at http://www.jennymag.org/spring-14-issue/prophetess. Her blog is Setting the Spirit Free, at http://painandspirituality.blogspot.com/.
No It Is NOT In My Head
written by Nicole Hemmenway

Review by Tara White, RN

This is an inspirational story that takes the author from the depths of pain and despair to the completion of a marathon. She tells her story chronologically, interweaving her progress in the marathon. Her story proves that chronic pain doesn’t define her as a person or control her hopes and dreams. Rather, she is “running for her right to live.”

The story begins with a very simple “high-five” with her best friend at a senior high school dance. Her hand missed and instead her ring finger and little finger made direct contact with her friend’s palm. Immediately, her hand throbbed, changed colors, swelled up with burning pain, and flexed into a claw-like position. This was the beginning of a nightmare of endless, horrific pain, multiple agonizing treatments, and ultimately being cast aside by the healthcare system. This was the beginning of Complex Regional Pain Syndrome or CRPS.

Along with the pain, she suffered the disbelief of her physicians. Some even said she just wanted to get out of school and simply sent her to a counselor. Inexcusable, this is all too common for many chronic pain patients. Disbelief takes away hope. Despair replaces hope. A good physician considers what to say to a patient. They exhibit expertise, yes, but also compassion and common sense. No patient should ever feel at the mercy of a physician they cannot talk with.

As it is for most CRPS patients, Hemmenway found being touched and examined extremely painful physically, while waiting years for a diagnosis depleted her mental reserve. She endured multiple procedures with little positive progress, including the placement and ultimate removal of an unhelpful spinal cord stimulator. She had finally exhausted the scope of medical technology known to her pain specialists.

Hemmenway had also tried Eastern medicine and alternative therapies. These gave her a glimmer of hope, and a way to regain her inner strength through guided imagery, the beauty of crystals, and the power of positive thoughts. She knew that she only had two options: to fight for recovery and a normal life, or to give up and suffer until death. Baby steps became her mantra. Every miniscule sign of progress was to be celebrated. Setbacks were to be expected, but there was always hope. After all, she writes, the universe wanted her to succeed.

At a loss, and praying for a physician that could really help her, Hemmenway and her parents finally saw a specialist in Corpus Christie, Texas. This was the specialist who would begin to change her life. He told her how many diseases began as a breakdown in the stress response system of the body.

He used Dynatron STS as a non-invasive therapy designed to calm and normalize the fight or flight responses in the nervous systems of CRPS patients. Using electrodes, the machine stimulated the nerves in different areas of her body. A low-frequency electrical current decreased the substances causing stimulation and increased the substances that cause relaxation. Although it took more than a year, this began to get the author on the right track. He also helped her get off a multitude of narcotics and other medications that were negatively affecting her health.

By now, years had passed. While there were many setbacks, there were also triumphant signs of remission. The symbolism of running a half marathon (13.1 miles) became the goal of her dreams. With her future husband at her side talking her through it, Hemmenway fights off the moments of wanting to quit.

These were the positive thoughts that she kept repeating to herself:

“I know I have to keep going. Surely I can finish the last mile of a half marathon if I can overcome chronic pain. As this race summed up my entire battle living with pain, I must keep my thoughts on how far I have come, how much I have suffered, and how I am now going to thrive.

“Although there were still bumps in the road that sidelined me, each time I bounced back quicker. My dark hours were fading. Like a flower coming out of its bud, I had blossomed.”

No It Is NOT In My Head, by Nicole Hemmenway.
http://www.nicolehemmenway.com
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