Every now and then we find ourselves at a point where we need to stop, look at where we are and where we have been. Life seems to go along “as usual” until something happens that forces us to take a long, hard look at our present circumstances. This is also true for people who are living life with chronic pain. At some point we need to reacquaint ourselves with the basics of pain management.

It does not matter how far we go in our journey from patient to person, or how well we might be managing, there will be times when pain—once again—demands our undivided attention.

Those of us who have traveled so far to get from patient to person may now have only a distant memory of how controlling pain can be. For others, a pain-dominated life is not that long gone and you realize that the balance between wellness and illness can be delicate. No matter where you are in your journey, the basics of pain management are essential to maintaining our wellness.

After all, that is what I had come to expect from treatments: temporary relief from the intense pain and an expectation that it would return and gain control of my life once more.

The fear that the pain would soon return only made me further value what I had learned in the pain program. That fear pushed me to incorporate all the skills I had learned into my daily life. It turned out that staying true to the program was what allowed me to remain a person—rather than a patient—these past 33 years.

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The Ten Steps

If there were a roadside guidebook on how to travel through life with chronic pain, it would be the ACPA manual, Patient to Person: First Steps. The manual’s theme is that while there is no easy cure or magic medication to relieve all pain, it is possible to regain control of daily life by directing our energies and thoughts away from pain and turning our attention to positive and constructive channels.

The Ten Steps at the core of the manual represent the philosophy of ACPA and are designed to help you make the transition from patient to person and improve the quality of daily living. By acquiring new coping skills and a positive attitude, feelings of helplessness can be replaced by hope and determination.

STEP 1: Accept the Pain
This doesn’t mean giving up. It means understanding that there may be no current cure and accepting that you will need to deal with the fact of pain in your life. Learn all you can about your physical condition so you can participate in managing your pain.

STEP 2: Get Involved
Take an active role in your own recovery. Follow your doctor’s advice and ask what you can do to move from a passive role into one of partnership in your own health care.

STEP 3: Learn to Set Priorities
Look beyond your pain to the things that are important in your life. List the things that you would like to do. Setting priorities can help you find a starting point to lead you back into a more active life.

STEP 4: Set Realistic Goals
We all walk before we run. Set goals that are within your power to accomplish or break a larger goal down into manageable steps. Take time to enjoy your successes.

STEP 5: Know Your Basic Rights
We all have basic rights. Among these are the right to be treated with respect, to say no without guilt, to do less than humanly possible, to make mistakes, and to not need to justify our decisions, with words or pain.

STEP 6: Recognize Emotions
Our bodies and minds are one. Emotions directly affect physical well being. By acknowledging and dealing with your feelings, you can reduce stress and decrease the pain you feel.

STEP 7: Learn to Relax
Pain increases in times of stress. Relaxation exercises are one way of reclaiming control of your body. Deep breathing, visualization, and other relaxation techniques can help you to better manage the pain you live with.

STEP 8: Exercise
Most people with chronic pain fear exercise. But unused muscles feel more pain than toned, flexible ones. Working with your doctor, identify a modest exercise program that you can do safely. As you build strength, your pain may decrease. You’ll feel better about yourself, too.

STEP 9: See the Total Picture
As you learn to set priorities, reach goals, assert your basic rights, deal with your feelings, relax, and regain control of your body, you will see that pain does not need to be the center of your life. You can choose to focus on your abilities, not your disabilities. You will grow stronger in your belief that you may live a normal life in spite of chronic pain.

STEP 10: Reach Out
It is estimated that one person in three suffers with some form of chronic pain. Once you have begun to find ways to manage your chronic pain problem, reach out and share what you know. Living with chronic pain is an ongoing learning experience. We all support and learn from each other and helping someone else can be the best medicine for helping yourself.

You can learn more about the Ten Steps in Patient to Person: First Steps. It was written by Penney Cowan, executive director of ACPA, with contributions from many ACPA affiliated professionals, in 1987 and most recently updated in 2004. In-depth articles about steps five through ten can be found in The Chronicle online archives (Winter 2005 through Winter 2006 on www.theacpa.org).
In learning to live with chronic pain, you have to learn how to live with other people.

Some people with chronic pain feel overly dependent on others—like their doctors and caregivers—or feel as if they are always asking friends to make accommodations for them. Operating in this mode, you may have trouble sticking up for yourself, or demanding your rights as a person. But you have a right to the things that you need and the behavior that you deserve, and you can ask for them without becoming aggressive.

People with pain may find it hard to express their needs and require that others respect them. But remember, when our needs are not met, tension is increased and our pain seems worse. Additionally, by not asking for the help and treatment that you need, your pain management can be compromised and your life become less fulfilling.

Read and reread these rights so they become part of your daily life. Remember, you do have the same basic rights that you grant to others.

You have the right to:

**Act in a way that promotes dignity and self-respect.**
You can refuse any request which makes you feel foolish or is not in your best interest.

**Be treated with respect.**
You deserve equal consideration as much as anyone else does.

**Make mistakes.**
Use your mistakes as learning opportunities and don’t dwell on the negatives.

**Do less than you are humanly capable of doing.**
Recognize that you have limitations and know when to stop. It is OK to relax and do nothing at all.

**Change your mind.**
There is no reason why you can’t change your plans or commitments if they become stressful or exhausting. Living with pain requires flexibility.

**Ask for what you want.**
If you don’t express what is on your mind, no one will be able to meet your needs. Speak up!

**Take time to slow down and think before you act.**
You don’t have to respond to requests right away. Be objective and consider the full implications before you commit.

**Say “no” and not feel guilty.**
You don’t always have to say yes. Be comfortable in your life and don’t extend your obligations beyond your limits.

**Not explain everything you do and think.**
When you are in an uncomfortable situation, you needn’t explain at length or justify your reasons for your actions.

**Ask for information.**
Particularly at the doctor’s office, you deserve to know everything about a medication or type of treatment.

**Ask for help or assistance.**
At some point you will need help, and this does not signify weakness. Plus, it gives someone else the opportunity to do a good deed and feel good about themselves. So go ahead and ask.

**Feel good about yourself.**
There is nothing wrong with liking who you are. There is no need to be ashamed of your condition. Be proud of the steps you have taken to regain control of your life.

**Disagree.**
We like to be popular and agree with others, but when we don’t express our true feelings, we can cause tension, stress, and increased pain.

**Ask why.**
When the purpose of a request is unclear, especially in talking to medical professionals, ask why. You deserve to know what is going on with your treatment.

**Be listened to and taken seriously when expressing your feelings.**
Your feelings are your interpretation of a situation. There is no right or wrong way to feel, and your response should be taken seriously.
ACPA Support Groups: Reaching out to Others

ACPA groups welcome anyone who is living with an ongoing pain problem. They do not focus on symptoms or provide treatment of any kind, but do offer education in basic pain management and life skills. In groups, people share what they have learned and encourage others to build more satisfying lives according to this philosophy.

- We do not dwell on physical symptoms of pain.
- We focus on abilities, not disabilities.
- We recognize and talk freely about our feelings about pain and its control over our lives.
- We do not make judgments and keep all group discussions confidential.
- We use relaxation exercises to help ease the tension that increases pain and refocus our attention away from pain and suffering.
- We use mild stretching exercises daily (with doctor approval) as a way to regain control over our bodies.
- We set realistic goals and evaluate them weekly so we can see that our desires can be achieved, one step at a time.

Visit the support groups section of the website to see if there is a group located near you. For contact information on the group you are interested in, call 800-533-3231 or email ACPA@pacbell.net.

What We Have Learned

For more than 30 years, ACPA has helped people with pain and learned a lot in the process. Here is a bit of that wisdom:

- We need the support of others who experience and understand chronic pain.
- Recognizing emotions helps us to understand ourselves.
- While our pain is certainly not all in our heads, attitudes and expectations do make a difference.
- Learning how to relax is essential. It helps prevent tension and redirects our attention on to other things we have some control over.
- Staying active, within realistic limits, can help us remain flexible and strong and reduce our sense of suffering.
- It is important to set realistic goals and chart our progress toward them.
- Chronic pain not only involves the person with pain, but the family as well.
- Hearing others talk of similar feelings and experiences caused by pain reduces our isolation.
- There are no wrong feelings.
- Half the battle is won when you begin to help yourself.
Ten Basic Steps Can Take Years to Learn

by Erin Kelly

Most people who become involved with the ACPA hear of the Ten Steps from Patient to Person. But when it comes to putting these basic principles in place in your own life, everyone finds their own challenges and comes to a personal understanding of how to travel through the basic steps.

Registered nurse Tara White did a lot of research on her own to learn how to live with her pain before she found the ACPA. “I pretty much came up with the same steps that Penney did,” White explains. “I was thrilled to find all of the steps together and presented so well,” she says. “I wish I had known about them sooner!” White now leads a support group in Citrus Heights, California with her co-facilitator Mary Shumate.

Acceptance can be Difficult

Accepting that there may be no cure for your pain is step one—and it’s a big one. “People say it’s the hardest step,” Shumate says. “It’s a big topic in the group.” And she herself is no exception. “I went to meetings for more than a year before coming to realize that this really applied to me,” she says.

Jana Hamik, an ACPA facilitator from Sebastopol, California, says she has accepted her pain but not the limitations it puts on her. “I recognize that I will have some level of pain for the rest of my life,” she says, “but I still struggle with the grief I have from the effect that pain has had on my life.”

She dislikes visiting hospitals or doctors’ offices—not because of bad medical experiences, but because it reminds her of the nursing career she had to give up. “It’s so painful for me to see nurses working—that’s where I want to be,” Hamik admits. She says that she uses this aversion as motivation to keep her self-care practices on track and avoid as many doctor visits as possible.

Calming Emotions and Relaxing Muscles

Hamik’s medical background also has influenced her belief that two of the most important steps in minimizing pain are recognizing emotions and learning to relax. She says that these two basic steps might have scientific importance in preventing the nervous system “sensitization” that some researchers believe contributes to chronic pain.

“The purpose of pain is to alarm us so that we realize something’s wrong,” Hamik says, noting that stress, fear, and anger can be part of that normal response. However, Hamik believes that her chronic pain arose because her nervous system became overprotective—too efficient at alerting her to potential threats—and started giving false alarms. “My back healed from its surgery 25 years ago, but I still have pain there,” she says.

“It’s not from a new injury, it’s from the changes to my hypersensitive nervous system.”

Hamik lessens pain by learning to recognize and defuse emotional responses and practicing stress-reducing relaxation techniques. “If you have a hypersensitive nervous system, you have to do what you can to calm it down,” Hamik explains. “When I feel twinges, I don’t think that I’ve been re-injured, but there is some anxiety that naturally comes up,” she says. “I have to override my body’s response.”

Many facilitators admit having trouble relaxing. “I’m always thinking about all there is to do and get done,” says Chelsea Nann. She does have a heavy schedule, as she facilitates an ACPA group in Marin, California, and is also a student. Even though she tries to make self-care a priority, relaxation rarely makes it to the top of her to-do list. “Frankly, it doesn’t feel like a priority,” Nann says. “I sometimes feel guilty for taking the time to relax—but I realize that it will help me through the rest of my day.”

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Ten Basic Steps Can Take Years to Learn
CONTINUED FROM PAGE 5...

Nann recommends setting a timer when you start work on a task and taking a relaxation break after 15 to 30 minutes. “Even a quick five-minute body scan can help you feel refreshed,” she says. Nann often uses a short audio relaxation program she found online for free. “I just pop it on my phone wherever I am.” The ACPA website also offers a five-minute relaxation exercise.

Priorities, Pacing, and Realistic Plans
Many of the steps can seem interrelated—setting priorities and setting realistic goals are two closely tied principles that can help you pace yourself and still feel productive.

Prioritizing can be difficult, since it requires you to give up some activities for others. “It’s important for those of us with chronic pain to recognize what is most important for our bodies and our minds,” says Nann. “For me, prioritizing may mean that I put off showering until tomorrow so I have the energy and stamina to get my homework done.”

Setting priorities also means making time for things you enjoy. White loves outdoor activities, and even though she has scaled back—giving up skiing, strenuous hiking, weightlifting, and riding a regular bicycle—she does find ways to pursue her physical hobbies by setting limits. “I ride a tandem bicycle with my husband, so I don’t have to do anything with my arms,” she says. “We rode 70 miles yesterday. I want to do some gardening today but I realize I might be pushing it,” she says.

Pacing yourself is part prioritizing and part goal setting. Hamik points out that many people find it difficult to get it right. “I think people tend to go one way or the other: either they push themselves so hard that they’re in tears at the end of the day or they become super sedentary,” she says. “They think they’re pacing themselves but they’re really avoiding activity.”

Hamik says that doing something enjoyable doesn’t have to involve an outing. “I studied dance in my teens and early 20s, and now I can turn on YouTube any time and see a ballet,” she says. She has a friend who has retired from coaching baseball but enjoys watching games on TV and keeping score. “You can keep up with things you are interested in, even if you’re doing it in a different capacity,” she says.

Focusing on abilities and maximizing positive emotions can be a powerful tool. Facilitator Sandy Rozelman believes a positive attitude is the most important factor in living well with pain. Her Cleveland, Ohio area group calls itself a “wellness support group” instead of a pain support group. “We wanted to meet with wellness on our minds, not pain,” she says.

Rozelman admits that keeping the focus positive can be very difficult, especially for people who have been struggling with pain. She uses coaching techniques to help them refocus on good things.

“‘If I say, ‘How are you?’ and the answer is ‘Fine, but my hip’s been bothering me,’ I’ll ask, ‘What about your other body parts?’” As Rozelman explains, “You have lungs and eyes and arms that are all working perfectly well without any attention; why are you giving so much power and attention to your hip?” She recommends that people focus positive attention and energy to the parts of the body that are working well, and ignore as much as possible the place that is sending negative messages.

She also uses redirection to help people who seem to be giving in to depression. “I’ll ask them, ‘What are you grateful for?’ Rozelman says that appreciating who is in your life and what you have—and perhaps don’t always acknowledge—can bring happiness back. “You can’t be sad or miserable when you’re feeling grateful.”
Beyond Ten Steps

No ten steps can cover everything you need to learn to live well. In helping others in her group, White also falls back on basics she learned as a nurse: the stages of grief outlined by Dr. Elisabeth Kubler-Ross. “People come into the group at all different stages,” White says. “We try to help guide them through the process.” She says that understanding the stages of grief can be helpful for people whose lives have changed. “I think it’s incredibly important to realize that there’s a natural process happening as you experience loss of ability,” White says. Hamik and Rozelman also emphasize the need to regularly practice the skills you need to stay healthy. “Being good to yourself doesn't mean taking it easy, it means that you do the right things to support your body,” Rozelman explains. One example is moving your body and exercising if you can, even on days when you don’t want to get out of bed.

“I know that if I stick to my anti-inflammatory diet most of the time, I can have a piece of my grandchild’s birthday cake and it won’t throw me into a flareup,” she says. Keeping up this practice has given her confidence and hope. “I exercise because I want to be able to walk when I’m 80 or 90,” she says. “Bad hips and hip replacements run in my family but that doesn’t mean that my hips will be bad. I am exercising and eating well to prevent future problems.”

Hamik says that although the self-care basics are simple and powerful, they can be hard to prioritize. “We’ll involve ourselves in endless searches for the best doctor or a cutting-edge cure for our pain;” she says, “but in many cases we haven’t made the basic, fundamental self-care adaptations that could give us a better quality of life.”

In some ways, the easiest answers can be hard to stick with. “If something seems too hard, people won’t do it, but if it sounds too easy, people won’t do it,” says Hamik. “They don’t see how something that sounds so simple could be effective.” They also think that simple steps don’t require regular practice. But practice, even on good days, is key to honing the tools for bad days. “When the pain is really high, it is difficult,” she admits. “That’s why we need to practice on a regular basis until it becomes natural and your body knows how to get there.” Hamik points out that relaxation for pain control is like any skill you want to learn: “If you want to play the piano or learn to bake a really great cheesecake, you need to practice that too.”

Reaching Out to Help Others

Step Ten is reaching out and sharing your experiences to help your peers. Although many group facilitators are naturally outgoing, they recognize the isolation that pain can cause, and how easy it is to make a difference in the life of another person.

Many facilitators have stories about group members who provide inspiration and role models for other members just by the way they live—handling difficult life situations with grace and creativity.

Shumate remembers the time when a woman who only occasionally comes to group meetings shared the guided imagery exercise she does every night. “She told the most beautiful story of the journey she takes in her mind,” Shumate explains, describing a vivid imaginary journey to a moonlit lake. “It was so peaceful. The room had a little magic in it that night,” says Shumate. “Even if she never comes back to the group, everyone who was there that night was impacted by that meeting.”

Basics for Life

As time goes on, many people find that their relationships with the basic steps change, but that they all are still meaningful. “I think the steps are all important throughout your life,” says Hamik. “The way you learn them and implement them will change and grow, but they’re all just as important all through your time with pain. There isn’t one I think you can check off the list and not return to it.”
“I think the Ten Steps take time,” says Shumate. “Some are easy to understand, but others take a lot of thought and can take years to really learn.” Some are a bit of both. “You can learn basic relaxation in an adaptive yoga class, but so much more can be added to it as your experience deepens,” Shumate points out. “It’s a constant learning process.”

When you might think you have a step mastered, it’s not unusual to find yourself struggling with it again, either because of a health setback or stressful life events. Nann has shared this experience.

“I struggle with different steps at different times,” she says. “I’m frustrated sometimes because I feel like I haven’t learned anything, but the reality is the exact opposite,” she says. “I’m just getting deeper into the issues and looking at the steps from a different place,” Nann explains. “I guarantee you’re a lot better off when you’re going through them the second or third time than you were the first time.”

Being involved with this article gave many of the people we interviewed an opportunity to review the basics. Shumate and White are focusing some of their meeting themes on the Ten Steps and the basic tools we can use to accomplish them. “I was surprised to learn that some people in my group had never seen the ‘Acceptance’ video,” Shumate says. (“Pathways through Pain: Acceptance” is available from http://acpa.stores.yahoo.net/pathpaacdvd.html).

“The steps give you confidence,” Shumate says. “We come to know that when things are bleak, we will make it through. You might have to lie down, use your guided imagery, calm yourself down,” she says. “It might take a week if you’re having a flare. But it’s not the end of everything.”

The steps give you confidence, Shumate says. “We come to know that when things are bleak, we will make it through. You might have to lie down, use your guided imagery, calm yourself down,” she says. “It might take a week if you’re having a flare. But it’s not the end of everything.”
AAN Publishes New Guidelines on Migraine Prevention
The American Academy of Neurology has published two guidelines that show many pharmaceutical, anti-inflammatory (NSAIDs), and complementary treatments can help prevent migraine attacks in certain people. However, only about 38 percent of the people who could benefit from these treatments actually use them.

“The strongest evidence we found was for the pharmaceutical treatments divalproex sodium, sodium valproate, topiramate, metoprolol, propranolol, and timolol, and for frovatriptan for short-term menstrually associated migraine, as well as for the herbal preparation Petasites (butterbur),” said guideline author Stephen D. Silberstein, MD, FACP, FAHS, FAAN. “However, there were several other pharmaceutical and complementary treatments with evidence for use, and still others with evidence against use or with insufficient evidence to make a determination regarding efficacy.”

Preventive treatments can reduce the frequency and severity of migraine attacks by more than half. However, epidemiologic studies suggest that migraine is a condition that is under-recognized and undertreated.

People using pharmaceutical treatments, complementary, or over-the-counter treatments may be unaware of the need for regular follow-up with their doctor. If migraines worsen or improve, dosages can be adjusted or people can switch to another drug.

The guidelines were published in the April 24, 2012, issue of Neurology®. You can read the migraine guidelines at http://www.aan.com/go/practice/guidelines.

Medical Musical Group Focuses on Chronic Pain
The Medical Musical Group has performed their “Healing for the Nation” concert series around the world. A chorale and symphony orchestra comprised of doctors, nurses, and others from U.S. medical centers and schools, the group shares messages of peace and international friendship.

MMG’s “Music with a Message” mixes music and readings to highlight health causes, bringing healing, hope, inspiration, patriotism, and peace. This year, their focus is on chronic pain, recognizing the work that ACPA is doing with veterans.

Medical Maestro Victor Wahby, MD, is a Senior VA Physician and a Fellow of the American College of Physicians. He wrote the award-winning “Veterans Hymn”. The Medical Musical Group is not a government agency. However, they are recipients of the Congressional Medal of Honor Society Bob Hope Award.

On November 9, 2011, the Medical Musical Group presented a Veterans Day Concert at the Basilica of the National Shrine of the Immaculate Conception in Washington, D.C. More information is at www.medicalmusical.org.

Study Suggests Similarities in Physical Pain and Emotional Pain
A study published in the Proceedings of the National Academy of Sciences has found that physical pain and intense emotional pain activate the same pain processing pathways in the brain.

Researchers tested 40 people who had recently experienced an unwanted romantic breakup that made them feel intensely rejected. Using functional magnetic resonance imaging (fMRI), researchers analyzed the participants’ brain activity during two “painful” situations, one emotionally related to their ex-partner and the other involving mild physical pain, similar to holding a very hot cup of coffee.

In both situations the same regions of the brain were activated, the secondary somatosensory cortex and the dorsal posterior insula. Both of these regions have previously been implicated in physical pain processing.

“We found that powerfully inducing feelings of social rejection activates regions of the brain that are involved in physical pain sensation, which are rarely activated in neuroimaging studies of emotion,” says researcher Ethan Kross, PhD, of the University of Michigan. “These findings are consistent with the idea that the experience of social rejection, or social loss more generally, may represent a distinct emotional experience that is uniquely associated with physical pain.”

Researchers say the results suggest that pain and social rejection may have overlapping sensory mechanisms in the brain. If confirmed by further studies, the findings may offer new insight into how social rejection may lead to various physical pain symptoms and disorders.

Step Up to the Plate—But Gently
When the Caregiver Becomes Cared For

by Janet Ruddock

It had to be Christmas, not summer, when my husband and I switched roles. I am the one with chronic pain and Frank’s loving, caring, and invaluable assistance is something I never take for granted. He is my rock. But in December it was Frank who tripped on an erupted hunk of asphalt, brutally sprained his right ankle, and broke his left one, requiring surgery and time off to recuperate.

All household duties fell upon me. Thank goodness for my twice per month house cleaners. Laundry piled up as we had just returned from Puerto Vallarta, Mexico, after a wonderful beach vacation with my younger son, his wife, and our adorable 18-month old grandson. I attacked said laundry only to find our dryer had died. As we await a replacement dryer, all wet laundry is hung up in every conceivable spot throughout our finished basement; it is not unlike living in a Laundromat gone amok.

As preparations sallied forth for our Christmas with family in Toronto, clearly Frank was not up to his usual helpful self. I became a whirling dervish of buying gifts, wrapping gifts, and carrying gifts to UPS, while packing festive travel wear for my husband and myself.

I was doing the opposite of everything on the “Stress Free Holidays and Travel Guide” for those with chronic pain. During a moment of complete brain fog, I decided the house needed outside wreaths lest we announce to roving burglars we were away for the holidays. Frank always performs this task with genuine enthusiasm. But now it was I who purchased, carried, decorated, and installed three amazingly-heavy-for-their-size evergreen wreaths. I drew the line at beribboned garland and outdoor lights along the picket fence.

My one person divide-and-conquer marathon took its toll. Mentally my mind was saying, “this too shall pass.” However, my entire body loudly declared, “Enough already!”

My left knee, always a bit of a complainer, cried out in pain and swelled up twice its size to prove the point. My troublesome right shoulder, never happy after an unfortunate dislocation and fracture years ago, announced, “Okay. I am now officially frozen. For good measure I’m sending tendonitis to your elbow and carpal tunnel to your wrist. Have we all made our point?”

Though sympathetic to the situation, my rheumatologist did mention overdoing it as he injected cortisone and analgesics into my knee and shoulder. An elbow brace and wrist support completed my festive holiday look.

We travelled to Toronto via airline handicapped services. With Frank in his wheelchair and me limping along behind carrying his crutches it’s anyone’s bet who looked more handicapped. At the rental car counter the agent anxiously processed the paperwork, no doubt wondering which one of us intended to drive. Much to the poor man’s relief, my older son turned up as designated driver.

Lessons learned. With chronic pain one must occasionally step up to the plate—but gently. I relied on my house cleaners. I discovered an invaluable grocery delivery service that we will continue to use long after Frank’s ankles heal. Neighbors, taxi drivers, even passers-by are glad to lend a hand.

Does it really matter if laundry piles up in unexpected corners? The cat, for one, loves it. I have learned that brain fog can result in mindless frenzy. And I didn’t heed the most important lesson: “listen to your body.” I paid the price, neither benefiting others or myself.

It is now mid-January and we have decompressed from our more or less relaxing Christmas with family. Traveling with Frank slip-sliding merrily, merrily through the snow on his crutches was not in the plan. If you are intending to break your ankle, do it in the summer.
There are never too many reminders of how important those basics are. In this issue of The Chronicle, we will focus on the Ten Steps From Patient to Person, the foundation of pain management.

To start, I’d like to comment on the first two steps, acceptance and getting involved.

Acceptance of pain seems to be one of the most difficult steps to understand. Some think it means to give up and allow the pain to take control. However, accepting the pain really means to understand there are no magical cures and there may be some level of pain that you will have to live with. Perhaps someday there will be advances in medicine that eliminate pain, but until then you need to be an active participant in your care. It is important to educate yourself, and learn as much about your condition as possible. The key is not to allow your pain to overshadow or control who you are.

Acceptance of one’s life has nothing to do with resignation; it does not mean running away from the struggle. On the contrary, it means accepting it as it comes, with all the handicaps of heredity, of suffering, of psychological complexes and injustices. —Paul Tournier

The natural next step is to ask, “What can I do to take an active role in getting involved in and managing my pain?” There are many things you can do:

❉ Become an active participant in your health care.
❉ Prepare for your visits with your health care provider.
❉ Listen to what your body is telling you and pace your activities around your abilities at that moment.
❉ Most importantly, focus on your abilities rather than your disabilities.

The ACPA has a number of tools, workbooks and a dynamic website designed to help keep you informed and engaged in remaining in the role of a person rather than a patient.

Greatness lies not in being strong, but in the right use of strength. —Henry Ward
Book Reviews

GrrrOUCH! Pain is like a Grouchy Bear
written by Cathryn Morgan and illustrated by Crystal Beshara

Review by Alison Conte

Understanding chronic pain and accepting it as a part of life is difficult for adults, let alone children. But even young children can have happier lives if they learn to deal with pain that infiltrates their families. A new picture book with this specific mission can help.

In GrrrOUCH! Pain is like a Grouchy Bear, Cathryn Morgan has used pictures and poetry to create metaphors for children to relate to when they are confronted with pain. Vibrant pictures of youngsters showing courage and sadness, along with animals in amusing fantasy situations, provide a way to teach children how to visualize and understand pain. This can help them develop vital coping skills for when pain disrupts their lives. A large helping of fun—in words and pictures—will make this a favorite story to read aloud, letting parents build intimacy with their children that will support the family in difficult times.

GrrrOUCH! Pain is like a Grouchy Bear begins by explaining the mystery of pain by saying that:

“Pain can be from an illness, accident, or disease.
Surprise! Pain can disappear or like a bully, tease.”

Pain can be emotional too, evoking the need to cry, talk, or shout. Everyone who has ever had pain can relate to this comparison:

“Pain is like a pretzel that twists and turns like a knot.
Sometimes you can feel the pain, and sometimes you cannot.”

Children are invited to imagine soaring above their pain like a kite or fighting it like a medieval knight. Techniques like relaxation and developing a total outlook are shared through simple ideas like listening to music, drifting away, and making others happy. Many people with pain have tried distracting themselves with fantasies, as recommended here:

“Pain can make you want to sleep, or keep you up at night.
What fun can you imagine, to relax and then sleep tight?”

Along with the grouchy bear, the rhymes compare pain to a snapping crocodile, a prowling wolf, a fierce dragon, waiting shark, slithering snake, and a slow-moving snail. Pain management skills are introduced through verses like this:

“Pain is really a feeling.
It doesn’t have to win.
Your body reacts to what you think and how you feel within.”

Children and adults will also appreciate these images, memorable symbols that bring pain management advice to life when other recommendations seem vague or overly technical. Sometimes pain does feel like a pretzel or a snake, waiting to pounce and steal the fun out of life. This book can put some of the fun back, for both children and their families.

Cathryn Morgan (www.cathrynmorgan.com) is an elementary school teacher who has also assisted children with special needs and pupils in English as a Second Language programs. Following a car accident in which she sustained injuries to her neck and back, she learned coping strategies to deal with living with chronic pain. Canadian artist Crystal Beshara (www.crystalbeshara.com) captures emotions through a variety of media, including pastel, watercolors, oils, and pen and ink. This is her third book.

Morgan received the Pain Awareness Award for 2011 from the Canadian Pain Society for GrrrOUCH! Pain is like a Grouchy Bear. It also received the 2010-11 Children’s Literature Award from the Elementary Teacher’s Federal of Ontario.

ACPA’s Growing Pains is a support group for chronically ill children and teenagers. For information, write to GrowingPains@pacbell.net or visit http://www.theacpa.org/conditionDetail.aspx?id=53.


The Better Bladder Book: A Holistic Approach to Healing Interstitial Cystitis and Chronic Pelvic Pain
by Wendy Cohan, RN

Review by Tara White, RN

Here is another wonderful example of a woman (an RN in this case) in chronic pain from interstitial cystitis, who doesn’t give up. Told by her physician that “there’s nothing else we can do,” she goes on to research and design her own successful treatment and recovery plan. This took years of trial and error with

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Memorial

both frustratingly hurtful and joyfully helpful treatments before she realized that a holistic approach was the way to go.

Interstitial cystitis is a painful and debilitating inflammation of the bladder lining and a common source of chronic pelvic pain. There are also other disorders which cause chronic pelvic pain. No matter the cause, it makes perfect sense that any treatment plan must begin with a true diagnosis and treatment of symptoms as well as potential causes and contributing factors. These include diet, managing stress, ways to reduce inflammation—traditional treatments as well as complementary practices. The author advises “leaving no stone unturned” in being your own advocate and detective looking for clues to help yourself.

To show how common this problem is, the author quotes from a large epidemiological study from 2009 that found that 3-6% of women over the age of 18 met the diagnostic criteria for interstitial cystitis. That would be over 4 million women. Additionally, the disorder is often misdiagnosed in men and some children may even be affected.

Cohan includes an introduction into the urological system, discussing how things are supposed to work for both males and females and what happens when they do not. She includes clear evidence that treating chronic pelvic pain is part of a systemic imbalance, suggests easy self-care tools, and describes other health conditions that could be interfering with recovery.

Cohan states that the role of diet is huge. She recommends everyone get his or her food allergies and sensitivities tested by a naturopathic physician, reasoning that when you find and eliminate your specific allergy trigger it will greatly reduce inflammation everywhere in the body, including the bladder. She also notes that it is important to neutralize the urine pH by eating an alkaline diet to reduce the stinging and burning of urination.

Inspirational case histories personalize the book’s dedication to encouraging and supporting those suffering from these painful disorders. Not only is there hope out there, but there are all kinds of helpful strategies that can bring reduction in pain and promote whole-body healing. Three appendixes provide gluten free diets, herbal and homeopathic remedies, information, and support resources.

Through her own two websites (www.wellbladder.com and www.glutenfreechoice.com) Cohan encourages readers to contact her and share how they are doing. This is an author who genuinely cares about her readers!

GWARY BENTFELD

Gary B. Bentfeld, 64, of New Middletown, Ohio, passed away Dec. 18, 2011. Gary participated in pain management rehabilitation at the Cleveland Clinic in the early 1980s and started an ACPA support group in Youngstown, Ohio in 1985.

He was devoted to the ACPA and that group until his death in 2011.

Penney Cowan remembered Gary as being willing to help the ACPA in any way he could. “He remained active as a person with pain, never falling back into the patient role. I believe his long-term involvement with his group helped him to maintain his wellness,” she said.


Gary had served during the Vietnam War on the U.S.S. Intrepid CVS II. He was employed as an assembler for General Motors until his retirement. Along with his ACPA work he was also active with many veterans associations, dedicating his life in service of the VFW and living as a patriot. Gary is survived by his wife, Earlyn, three brothers, two sisters, and many nieces and nephews.
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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Thanks to these corporations for grants that enable ACPA to fund special projects:

**Endo Pharmaceuticals** has provided a grant to expand ACPA’s campaign of public service announcement videos on opioid safety.

**Pfizer** has provided funding for a new program focusing on diabetic neuropathy called “Discuss Pain Now.”

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.