

CHRONICLE



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hen we consider pain treatments, we think about all of the years of X-rays, CT scans, surgeries, physical therapy, counseling, and tests. These are the "normal" approaches to pain management, but our personal, day-to-day therapies are different. What do you do to help yourself cope?

We each find therapies that apply to daily life and stick with what works. The techniques that the American Chronic Pain Association teaches help to reduce our sense of suffering while improving quality of life and increasing function. Throughout the ACPA's 33 years of helping people manage their pain, we have continued to be open to learning new coping strategies and passing them along to you.

For instance, many people use art or music to cope with pain. I don't think

I would have ever considered it a coping strategy before I went to a pain management program 34 years ago. As part of our regular daily activities, we went to creative therapy and experimented with a variety of art forms, such as leather work, copper enameling, or other crafts. I didn't realize it at the time, but I often got lost in the process of creating. It gave my mind, and in some sense, my body, a rest. It didn't matter what I created; it was the process that mattered.

Later, I found that having ACPA support group members create their own art during a meeting was somehow very calming and satisfying to everyone. I was amazed at the creativity of the members. They seem to lose themselves, just as I had at the pain management program. When we added music, it turned into an even better meeting.

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PAIN Exhibit Artwork Makes Pain Visible

by Alison J. Conte

rtists who perform music, paint, embroider, or make jewelry often become fully absorbed in their craft as the outside world fades away. So it is no surprise that the arts—whether you create them or simply enjoy them—can be a sanctuary for people with chronic pain.

For many of us, the arts are a distraction and help us to relax and ease tension, both decreasing pain and giving greater purpose to life.

People can also use their art to express the turmoil of emotions that come with living with pain. And of course, the beauty of art, in all its forms, gives us something lovely or exciting to focus on. This can be a lifeline when your daily emotions hover between anger, sorrow, and bitterness. It can even be an actual life saver.



Mark Collen of Sacramento, California, knows this all too well. He is an artist who developed chronic pain from a herniated disk in his lower back. "Because I didn't appear to be physically injured, I was unable to get my doctors to understand how bad the pain was," he said.

Close to suicide, he created a mixed-media work of art called *Chronic Pain*. It shows a face covered in packing tape with only one eye peering through, in a jagged pale field surrounded by black. He describes his state of mind this way:

"...Falling again into the abyss

The taste of suicide is delicious in my brain

....There are moments when a ray of hope filters
through the darkness
but it is too black to make a difference
I escaped before, but it found me again"

This was the first work of art Collen did about his pain, and it helped him get through the crisis. Moreover, when he showed it to his doctors, the visual reference allowed the physicians to better understand his pain by seeing it through his art.

"It was then I understood how beneficial art could be, and I began wondering if other people had made art about pain," Collen said. In 2003, through fliers posted in the offices of pain specialists, Collen found other artists and started the PAIN Exhibit, a website for art related to pain. Artists found him and began to contribute their work.

The initiative soon grew into a community of artists who use art to communicate the experience of living with constant pain and get better medical treatment as a result.

Making Pain Visible

Today PAIN Exhibit, Inc. is a non-profit art exhibit at www.PainExhibit.org. James Gregory, who also lives with pain, is the creator of the website and an integral part of PAIN Exhibit, Inc.

As of July 2013, the PAIN Exhibit included 101 pieces from 76 artists. Artwork is shown through 11 thematic galleries, which express different facets of the pain experience. "The art itself created the themes," Collen said. "As artists contributed, it fell into categories."

Collen is always looking for new art, which can be submitted online at http://painexhibit.org/new-pain-exhibit-entries/.

The galleries reflect aspects of living a life with chronic pain: Portraits of Pain, Pain Visualized, Suffering, Isolation and Imprisonment, Mental Health, and But You Look So Normal. The artists also find positive inspirations in their conditions, creating images that depict Escape from Pain, Unconditional Love, and Hope and Transformation.

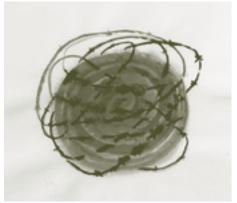
The art includes paint, watercolors, sculpture, and collage, and a wide variety of styles. It expresses pain in a way that words cannot, but many pieces are accompanied by descriptions written by the artists, such as Resonance: Erasure by Susan Gofstein: "In the absence of speech, a visual language of metaphor is a constructive tool, creating artifacts that can function as the speaking self."

In 2012, Collen converted the PAIN Exhibit to a non-profit organization that could accept donations to assist its mission: "To educate health care providers and the public about chronic pain while giving a voice to the many who suffer in silence."

"There are professional artists and art therapists who have made art about their pain, but PAIN Exhibit is a way that



"Do You See What I Feel?" by Dana Harrell-Sanders



"Fire Contained" by Helen Tupper



"Self Portrait, Green Shirt" by Sterling Ajay Witt



"Lucca" by Cynthia Yolland



"Seeds of Destruction" by Marianne van Gelder

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people with chronic pain can express some facet of the pain experience," Collen said. "It elicits an emotional response when words don't. The pain is what gives the art power."

"People have used these images to show their physicians. The response is very positive, because with good communication, care improves," he added. "People with pain are frustrated because pain is an invisible disease. This art makes pain visible."

Reaching out Through a Community

Another major benefit is that the PAIN Exhibit helps people with pain feel less isolated, that they are not alone in their feelings or their art. The exhibit transforms their pain experience into something positive that can be shared to help others.

PAIN Exhibit images are used by health educators, art therapists, pharmacologists, and physicians internationally to educate others about chronic pain. Professional publications have used art from the PAIN Exhibit on their covers. The fees from such publications help to promote the site.

Collen hopes to one day publish a book of pain-inspired art for use by clinics and pain rehabilitation centers to help patients and doctors communicate.

Collen studies the medical literature in the field of pain treatment, and has published articles in professional journals. His writing relates a personal perspective on medications, placebos, and pain therapies. In 2008, he was responsible for recognizing a new condition, Pain Insomnia Depression Syndrome, in his article: "The case for Pain Insomnia Depression Syndrome (PIDS): a symptom cluster in chronic nonmalignant pain" in the Journal of Pain & Palliative Care Pharmacotherapy.

Collen works in oils, photos, sculpture, and mixed media. Besides art, his other pain management tool is exercise. "It keeps me stronger and flexible, and helps to control the mental illness that comes with pain," he said.

"I've made a lot of pieces about pain and suffering. Pain is loud in my life, so it is a source of inspiration," said Collen. "But I do a lot of art that isn't about pain. Pretty pictures make my brain happy. We need that too."

Music Therapy as an Integrative Treatment for Pain

by Joanne Loewy, Suzanne Hanser, John Mondanaro

The Ethos of Pain

There are a variety of ways to classify pain. The most common way is to relate pain to its source or to affiliate it with a diagnosis. Another way is to categorize pain according to its intensity and/or duration. Typically, acute pain is severe and may be extremely intense. It is thought to be shorter-lived than chronic pain, which may involve a predicted discomfort as part of a chronic condition.

Episodes of pain occur when tension activates muscle strain, resulting in a stress response. The brain computes a response to this pain, which results in a change of biochemistry, affecting cortisol levels among other indicators. A "cycle" of expectation and habituation may prompt a person experiencing pain to seek intervening relief.

Pain, whether nociceptive (caused by a painful stimulus) neuropathic, or inflammatory, is a symptom that is often treated with medications called "pain-killers." Prescribed medication may break the cycle of a painful episode's recurrence; however, reports of pain being poorly treated or breakthrough pain episodes are not uncommon. Pain of unknown origin—"idiopathic pain"—takes its victims from many common diagnoses, such as back pain, fibromyalgia, and headaches, where medical practitioners find no apparent cause for painful symptoms.

In recent years, our theoretical understanding of pain has broadened. Today, the "neuromatrix" model of pain describes an integrative foundation of systems that determine the perception of pain. When pain is triggered, the person perceives a weaving of experience, and most particularly, an interaction between a wide array of dimensions inclusive of, but not limited to sensory, affective, evaluative, postural, and other domains of function (Malzack & Katz, 2004, p. 23).

Music Therapy

Since the beginning of time, humankind has addressed music as a source of universal energy. From Pythagorus' harmony of the spheres to accounts in the Bible of David healing Saul with his lyre, there is general consensus that music can soothe and tame.

Music therapy is a common and growing treatment remedy for people in pain. For acute episodes during a pain crisis and for lingering pain resulting from a chronic condition, music therapy is becoming a well-known analgesic. It is an effective therapy as an in-the-moment treatment for an increasingly pain-stricken population.

Its popularity is growing in hospitals and clinics, and within particular treatment regimens where music therapists assess

and evaluate. Researchers and clinical practices are placing stronger emphasis on methods that integrate music into daily care. Implementing music therapy into the plan of care for patients in pain—and their caregivers—translates into safe, preventive, cost-effective, and symptom-focused treatment.

Music therapists have a unique vantage point in treating people in pain. By "playing" music with a patient, they can access the dynamic nuances of the actual moment of pain. Whether the music expresses rage or confinement, the therapist can work within thematic and dynamic expression without words or intellectualizations, and address the raw "feeling" of those moments.

Assessment and Treatment

Accurate assessment is most critical to effective pain treatment. Using Color Analysis Scale (CAS), researchers at the Louis Armstrong Center for Music and Medicine at Beth Israel Medical Center in New York City are able to depict significant themes related to the expression and interpretation of clinical nuances in a variety of diagnoses and settings where pain commonly occurs in the hospital. Rather than patients simply defining their pain by assigning an often-arbitrary number or musical sound to their discomfort, the CAS instrument provides a means for patients to indicate intensity, possible comorbidities, beliefs (inclusive of culture), and anxiety—all important indicators of the total pain experience.

Pain, Tension, and Release

Pain and tension are inextricably connected because they are simultaneously experienced, and occur in a cycle of cause and effect. The recently published text, *Music and Medicine:* Integrative Models in the Treatment of Pain (Mondanaro & Sara, 2013), offers a broad span of pain treatment interventions that can address both acute and chronic pain.

Preliminary findings of research nearing completion by music therapists and physicians at Armstrong Center (www.musicandmedicine.org) indicate impressive effects of music therapy on pain experienced by patients recovering from spinal fusion surgery.

Music therapy interventions (inclusive of release strategies) help individuals become mindfully present, not only of their pain, but also of their own inner resources for coping.

Music is also comprised of cycles of tension and resolution. This cycle can be found in music styles from the Baroque music of Bach to the hip-hop/rap of Eminem. Music therapists providing pain treatment seek a common preference in music, making an individual's therapeutic relationships more effective.

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In the operating room,
Dr. Joanne Loewy, director
of The Louis Armstrong
Center for Music &
Medicine, assists general
anesthesia with music
therapy and calms
Suzanne, a 45-year-old
patient about to
have surgery.

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The tension/release intervention is a joint venture of therapeutic alliance, where the therapist and the patient together focus on achieving the desired release. The use of mindful breathing accompanied by visualization can be supported by live music created by the therapist, or through mutually created music when more active participation is possible.

Drumming is a primal option and a means of musical expression that bypasses the usual pressures inherent in creating "pretty" music. The rhythms of breathing, which involve the heart, pulse, speech, and gait, are all natural functions. Attention and emphasis on the cycles of tension and resolution within these rhythms can be reinforced through the use of volume and tempo, and in the building and releasing of musical tension.

Children in Pain

Music therapy serves the needs of children and adolescents experiencing pain through verbal and non-verbal uses of music. Whether through the spontaneous play of toddlers or the personal assertion of identity of adolescents, music can provide a necessary forum to give voice to a child's pain experience.

Children of all ages may present their pain experiences across a wide range: from stoicism to overt expression through inconsolable crying. For toddlers and younger children, crying not only serves as an expression of immediate pain, but as expression of fear, anxiety, and frustration with the lack of control, so often beyond the child's cognitive and verbal capacity to articulate.

For this reason, commanding a child to stop crying can invalidate such authentic expression. The patterns for trust in caregivers and the building of lifelong coping skills are established early on in one's life. The toddler who is repeatedly admonished for expressing pain authentically is deprived of valuable opportunities for the building of self-esteem, self-confidence, and control (Mondanaro, 2013).

Adults in Pain

Similarly, adults often need to be reminded of their inner resources for coping with pain, and introduced to creative strategies for managing pain. Fortunately, there is a growing body of evidence that supports the efficacy of music therapy. A systematic review of 51 randomized controlled trials with 3,663 individuals (Cepeda et al, 2006) established that music has the potential to decrease the perceived intensity of pain. The study also found that music lessened the need for medication in conditions of acute, chronic, and cancer pain. This was the case even when individuals merely listened to music.

Live music can be very effective. For instance, a woman experiencing the acute pain of childbirth contractions may be led to focus on music as a positive, meaningful stimulus, much like a visual focal point (Hanser, 1983). Listening to music that is "ear-catching" has similar impact.

During childbirth, diverse music interventions provide a variety of coping techniques that flow with the evolving nature of the pain and the experience as a whole. In addition to riveting the attention, music can change the mood of the expectant mother, as well as those around her. Here are some music therapy strategies that are useful not only in childbirth, but also with acute or chronic pain (Hanser & Mandel, 2010).

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An Artistic Approach to Pain Management

by Erin Hart

rt therapy has shown tremendous benefits in helping individuals cope with the negative feelings associated with any illness—from cancer to anxiety to depression. The creative outlet helps the affected accept their "new normal," improve sleep, and enhance their overall outlook on life. Even Vincent Van Gogh reportedly used to his art to manage his various ailments.

For these four individuals with chronic pain, art has become a source of inspiration and relief.

Embracing her Creative Identity

As a child, Mary Eigel could never understand why she wasn't able to run and jump as fast or as high as her friends or play outside much. When questioned about her inabilities, her parents wouldn't answer her—instead directing her to more creative pursuits, such as painting, sewing, and crafts.

Although she enjoyed her childhood and the time she spent with her seamstress/designer mom and oil-paint loving father, she didn't understand the secrecy. At age 11 when puberty began, and was accompanied by back and leg pain, her parents remained silent. Finally, at age 25, she had her answer: hip dysplasia. Although she had surgery as a toddler to help reposition her femurs, Eigel's condition remained.

"My parents' secrecy probably had a lot to do with not wanting me to feel different—to believe that I couldn't do things," Eigel said. "My parents were devout Catholics, and they believed that suffering brought merit. They encouraged my artistic side as a way of forging my identity—something that's hard to do being the eldest of six."

She ran with her creative identity. She immersed herself in high school arts classes, majored in art in college, and received her master's degree in the same field. Eigel taught high school art for six years—struggling many days just to make it through the day. But sharing her passion with others was her medicine.

"When I was really engaged in making art or teaching it, there wasn't room for pain," she said. "It was food for my soul and nourished me in places that were depleted."

From Theory to Practice

After her second child was born in 1983, she gave up teaching full time. Three years later, she set up a painting studio in her St. Louis, Missouri, home. The in-home studio allowed her to experiment with watercolor, distract herself from daily pain, and spend more time with her kids. The result was a stronger mind-over-body connection. She began exhibiting, selling, and winning awards for her art. In 1990 and 1991, she finally had hip replacement surgery. In this "second life," she was pain



free—for the first time ever. And it was paralyzing. Eigel said her brain became confused without the pain and believed she was incapable of regular activity. The disbelief began to resolve as she worked to mend emotional and mental disconnects.

In 2003, her life course changed again. A panel truck hit her car and plunged her "back into the pain hell hole." The accident caused a soft-tissue injury and a knotted piriformis muscle.

Attempting to return to a pain-free state, she began trying alternative therapies to manage her pain: reiki, healing touch, acupuncture, Chinese herbs, a modified diet, aquatic exercise, and more. She also helped start a pain support group in her area in 2006 and then connected with the ACPA in 2009.

A New Art Form

Unable to sit comfortably to paint, she began writing—following in the footsteps of her daughters Allison, 36, of Oakland, Calif. and Katie, 29, of Chicago.

"I began writing about feeling like a hostage: the pain was inside of me and it called the shots," Eigel said. "Katie got me into blogging, so I started my own about my pain journey (http://bluestarmoon.wordpress.com). I am also editing a book describing my mind, body, spirit experience with pain and the downside of not allowing a child to talk about it."

For the most part, Eigel remains pain free—taking only acetaminophen as needed for arthritis flare-ups. She and her husband George play water volleyball weekly. Since 1998, she has taught digital art classes, healing arts, and other art-related workshops, and even traveled to Ireland to paint freehand and digitally on Galway Bay. "I found that identity in art because it was always a positive stimulus," Eigel said. "Immersing yourself in beautiful things is inspiring and allows you to totally engage with the moment."

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Unexplained Changes

For 37 years, Cindy Todd of Arroyo Grande, California, was an active outdoorswoman, hiking, camping, and kayaking. But in 2008, much to her surprise, those activities became more difficult. She began having almost severe, almost constant pain throughout her entire body, as well as other symptoms such as horrific rashes, debilitating fatigue, and mouth sores. She, her partner, and her doctors were befuddled.

In 2011, after three years of unsuccessful consultations and treatments, she finally had a diagnosis from a rheumatologist at the University of Southern California (USC) Medical Center: a rare auto-immune disease—Behcet's Syndrome. Also known as Behcet's Disease, the affliction can be inherited and cause inflammation in many areas of the body, such as joints, backs of the eyes, and more.²

Todd, 42, and her doctors suspected that an industrial accident—which caused an underground leak of the gasoline additive MTBE into the water table—triggered the disease, as her symptoms began shortly afterwards. Later, DNA typing revealed that she was predisposed to the disease and that the toxin likely set off the symptoms.

Finding Inspiration

Although gaining a diagnosis was a relief, Todd plunged into a depressive state, hating the constant pain and the meds she needed just to make it through the day.

"I was in such a bad place that I didn't know if I could pull myself out of it, "Todd said. "Finally, I realized I had to find what inspired me, because my life wasn't over. For me to not

"Look around and figure out what moves you. Go to art museums, look around and experiment with different forms of art. It doesn't have to be just one medium. And don't judge whether or not you are good at it — what matters is that you enjoy it and are benefiting from it."

lose the physical aspects of my life, I had to address my emotions—and this is where my art became crucial."

As a child she dabbled in art. Although she enjoyed it, she never felt capable. Now, needing a soothing activity, she immersed herself in abstract painting—a style, she says, that affects each viewer differently. She found herself so in tune with her work that she blocked all external stimuli, including her pain, for hours on end.

"I don't know what comes over me—other than I just let go," she said. "So often in society, people are uncomfortable talking about disease, despair, and pain. Here, I release myself from those social walls and from the pain. I get to an almost meditative state, which lasts several hours after I'm done painting."

Often, she paints for long periods, whenever she can find spare time, allowing the emotion and pain to spill onto the canvas. Occasionally, she walks away from the activity for months, because she doesn't feel well or just isn't inspired. There are also times when she'll come back to a painting and destroy it, much to her family's consternation.

Sharing the Benefits of Art

Despite the on-again, off-again nature of her painting, it has been beneficial. Although Todd hasn't actively talked about her art at support group meetings, she has begun sharing her journey with some of her co-workers who have painful health issues. She recommends they find something that feeds the soul and addresses the emotional aspects of a health problem—something that medications don't always solve.

Currently, Todd is creating a series of paintings that highlight "the fusion of art and disease." She has finished the first, and is hoping to exhibit the series at her local art museum and other charity art events.

She encourages anyone on a similar pain journey with an interest in art to find their passion—and not be discouraged if the results aren't picture perfect.

"Look around and figure out what moves you," Todd said. "Go to art museums, look around and experiment with different forms of art. It doesn't have to be just one medium. And don't judge whether or not you are good at it—what matters is that you enjoy it and are benefiting from it."

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An Artistic Approach to Pain Management

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Challenging Brain and Limbs

Cindy Burgener, 40, of Greencastle, Pennsylvania, was diagnosed in 2008 with reflex sympathetic dystrophy (RDS) in her right arm, a condition that erupted soon after she received a cortisone shot meant to help her long-time tendinitis condition. Also known as Complex Regional Pain Syndrome, RDS is a chronic neurological syndrome characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. Six months later, the condition moved to her left arm.

Although the pain wreaked havoc with her body, Burgener said she was not willing to let it take over her mind. She tried several alternative therapy methods, such as a stellate ganglion cervical nerve block, physical, occupational, and aquatic therapy. But she wanted to find something that both challenged her brain and her limbs. So she settled on scrapbooking—an art that has allowed her to add beauty to both the past and the present.

"I found that scrapbooking provided me with the opportunity to focus on creating something beautiful. But it wasn't easy initially. I struggled to hold small pieces with my hands and tools, and dropped things frequently. And when that happened, my hand stayed in the same position, as though it was still holding the object. At times, my hands would even begin to spasm," she said.

Burgener's occupational therapist recommended scrapbooking at least one day a week. She was asked to focus on improving her concentration on each step—from holding the tool to placing the embellishments on the page. After several months, Burgener improved her fine motor skills, range of motion, hand-eye coordination, and overall hand and arm functionality.

Scrapbooking has also helped desensitize her arms, which, because of the RDS, had become hypersensitive to touch.

Embellishing the Past and Present

One priceless gift that chronic pain has given her is one-on-one time with her 12-year-old daughter Meghan, who is Burgener's scrapbooking buddy. Each day, they spend time sorting through photos, selecting embellishments for each page, and determining how they best can tell a story.

Although her RDS has slowed her down, Burgener uses that time creatively. When her pain forces her to take multiple breaks, she uses the time to take notes about a particular page, sort through photos or talk with her daughter about different design aesthetics. She's become accustomed to this modified approach—but it wasn't easy to accept in the beginning.

"It was really hard to accept my limitations and the fact that I couldn't do the things I did before," Burgener said. "It took me about two to three years to make peace with it, and I don't think I'll ever fully accept it. I always feel like I do can do better—or do more."

Doing More for Others

In 2011, she began facilitating an ACPA support group, which disbanded because members were unable to meet in person. She still connects with former members by phone, mail, and email and offers support when needed. In addition, she has taught scrapbooking to children with behavioral disorders or autism to improve their focus and conduct.

Pain with a Purpose

Burgener's life may be different than anticipated—but it is full of gifts. Last month, she celebrated her 21-year-old son Brandon's wedding. In Spring 2014, she will attend two graduation ceremonies: one for Brandon from college and one from high school for 17-year-old Brayden.

Although her condition can cause severe pain and limit certain activities that she used to do, such as bowling, snow tubing, or playing catch with her kids, she finds other ways to bond with her family, such as cooking or date nights with her husband, and scrapbooking with Meghan.

"Scrapbooking has truly given me a purpose," she said.
"Chronic pain makes you feel worthless, to the point that you question your abilities and what you can do for others. Finding this outlet has enabled me to give back to others and create something beautiful in the process. I was worried when I was diagnosed that I wouldn't be able to put myself back into the place of giving, but scrapbooking has given me that opportunity again."

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Feeding the Soul

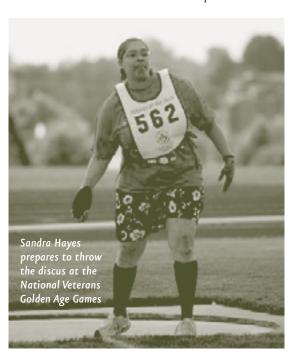
Art has always been an integral part of Sandra Hayes' life. From the time she was seven, she would draw pictures and use paint to enhance them. When she tired of that activity, she would sing or listen to music—anything from rhythm and blues to smooth jazz to gospel music. She also loved singing in the youth choir. However, Hayes never anticipated then that these interests would do more than feed her soul.

For most of her life, Hayes had experienced low back pain. In her teens, she began having trouble standing. The problems seemed to fluctuate in keeping with her menstrual cycle. She also began to suffer from depression, which was later diagnosed as bi-polar disorder.

Hayes was eventually diagnosed with fibromyalgia and rheumatoid arthritis (RA). The latter, she said was a complete shock because of her age. Gone were the days of playing softball, which now, because of the RA, caused only fractures.

Needing something outside of medication to soothe her emotionally and physically, she began listening to music—especially at bedtime. Music, along with salt baths or oils, helped settle her body and mind and allowed her to sleep. When she moved to Anchorage, Alaska, she joined a choral group as a tenor/baritone, as well as an Anchorage band, for which she plays percussion.

"Singing and playing instruments help pull my mind away from the pain and allow me to focus on something else," she said. "When I'm playing percussion, the rhythm and the beating allow me to air the frustration that pain has caused in my life."



Alternate Art Forms

When the chorus and band are on hiatus in the summer months, Hayes, now 62, finds other activities to keep her busy. She is "mom" to two Chihuahuas, who function as her service dogs. She enjoys word or picture puzzles, as well as photography. Recently, she spent an entire day at McHugh Creek in Anchorage. There, she sat high on a mountain overlooking a body of water, taking in the vistas with both her eyes and her camera.

When she's not scaling natural wonders, she's busy completing coursework for three technology degrees at the University of Alaska Anchorage. In addition, she volunteers at the local VA center, where she frequently uses her artistic skills to develop PowerPoint presentations for co-workers.

In 2010, Hayes began leading her local ACPA support group. In addition to sharing their pain journeys, group members dabble in music, arts, exercise, or other favorite activities. They all learn new coping strategies, and build a sense of teamwork and trust.

"I encourage everyone in my group to start with something they love the most—and to do only what they can handle," Hayes said. "I also tell them not to be afraid of trying new things—or feel like they aren't doing something the 'right' way."

Family and Friendly Competition

Hayes is devoted to her daughter and two grandchildren, and others that have adopted her as mom and grandma. On weekends, she can be found playing Wii or Xbox Kinect with the grandkids or making a big family breakfast on Sundays.

A former member of the Air Force, Hayes also participates in the National Veterans Golden Age Games, one of the many activities that the U.S. Department of Veterans Affairs sponsors. She competes in the shot put, discus, javelin, cycling, and swimming—bringing home gold and silver medals. For her, being active is every bit as much of an art form as are her singing and music.

"When I'm in my element, I'm not thinking about what's going on with my body," Hayes said. "All I'm thinking about is the people I'm with, the activity I'm participating in and the fun I'm having."

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- 2. http://www.medicinenet.com/behcets_syndrome/article.htm
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Pet Rabbits Prove Therapeutic for Pain

by Nancy Laracy

hat could be better than a soft, cuddly adorable bunny to divert the chronic pain of fibromyalgia and an autoimmune disease?

I am a pet therapist who shares the healing properties of rabbits with children and adults who are sick, sad, or in pain. While most of us are used to hearing about therapy dogs and cats in hospitals and nursing homes, bunnies are the newest therapy animals on the radar.

Animal Assisted Therapy (AAT) is proving to be a very vital, effective alternative treatment for pain. Two scientific studies illustrate the beneficial effects of AAT for chronic pain.

On Nov. 17, 2009, <u>Science Daily</u> reported that adults who used pet therapy while recovering from total joint replacement surgery required 50 percent less pain medication than those who did not. It stated: "Evidence suggests that AAT can have a positive effect on a patient's psychosocial, emotional, and physical well-being."

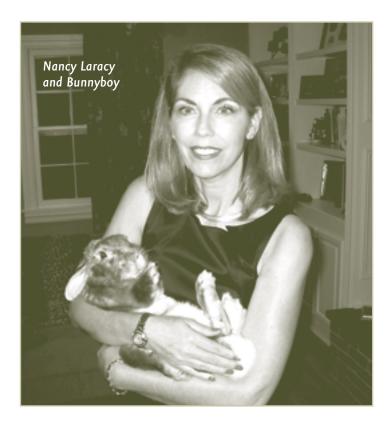
In January 2012, <u>Pain Medicine</u> reported that therapy dog visits in an outpatient setting could provide significant reduction in pain and emotional distress for people with chronic pain. AAT also significantly relieved the emotional distress and enhanced feelings of well-being for accompanying caregivers and the clinic staff.

A Journey through Pain – with a Bunny

I discovered the healing nature of loving, playing with, and caring for rabbits, specifically a rabbit named Bunnyboy, some years ago when my seemingly perfect life went off course. What should have been a routine viral infection turned out to be anything but. Suddenly, at 36 years, I found myself living with chronic pain while trying to raise my two beautiful children.

Initially, I tried every mainstream treatment to cope with the pain. However, when one terrifying reaction to a medication sent me to the emergency room, I realized that I had to find a new approach. I started going to a chiropractor, had weekly massages, walked on an underwater treadmill to relieve the pressure on my joints while strengthening my muscles, and forced my husband to sleep on a magnetic mattress designed to relieve pain. In the meantime, I taught myself to say "I need to manage my pain," instead of saying "I have to get rid of this pain."

Then, in the middle of a blizzard, by a stroke of luck (or perhaps fate) I bought an adorable Red Satin rabbit that became my avenue to overcoming chronic pain.



If you deal with chronic pain, your first thought may be that you don't have the energy anymore to take care of a pet. Bunnyboy, who was born with an immune system disease much like mine, needed constant medical attention on top of the normal care required by most pets. But I quickly found that I was on the receiving end of pet therapy.

I got up every day and cleaned his litter pan, fed him, drained his chronic abscesses, and administered his penicillin injections. And I played or cuddled with him as though he was my third baby.

He loved to be chased—racing around the house similar to a Nascar driver. He binkied across the room—suddenly rushing around at random while leaping and twisting in the air.

Unconditional Love on Four Feet

Bunnyboy suffered from so many ailments, yet he hopped around the house with a zest for life that amazed and inspired me. He never gave up and helped me not to feel so broken. Bunnyboy taught me that it was okay not to be able to do everything I used to. He could sense when my pain was the worst and he would snuggle deep in my armpit or sprawl across my chest. The warmth of his small furry body soothed my pain.

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Music Therapy as an Integrative Treatment of Pain

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Listening to Music

Breathing with familiar music: If pain is not extreme, breathing deeply to slow, flowing melodies may be effective. When pain is acute and severe, however, music with a strong beat is advisable to guide a regular and predictable tempo for breathing. Inhaling deeply and exhaling shorts puffs of air accompanied by fast, rhythmic music is another helpful, focusing technique.

Imagery and memories: Imagining beautiful images or meaningful memories evoked by music, or identifying music that brings up beautiful places in the imagination, may transport a person far away from the source of pain and elicit a sense of peace. Music that is associated with wonderful times, people, and places can evoke the same pleasant sensations that were originally experienced. With closed eyes, the listener pays particular attention to changes in the senses that come about with that memory.

Being guided by a music therapist: A music therapist brings live music that ebbs and flows with the person's experience. In one technique, the therapist plays a musical representation of the pain, and when the music slows and fades, it persuades the listener to imagine the pain diminishing. In another music therapy technique, the therapist slows down the music, while the person breathes along, gradually relaxing.

Active Music Making

Actively creating music or improvising on instruments: Playing instruments offers a physical release that can be cathartic. Musical improvisation offers an expressive outlet for inner experience that often communicates better than words. Through musical explorations, one may discover a source of hidden creativity. The challenge of creating beautiful music hones concentration onto something positive outside of pain.

Moving to music: Finding ways to move and dance to music exercises the whole body, while also working out tension. When pain exists in one part of the body, it is likely that other areas of the body will be tight, and surrounding muscles will contract. Moving and dancing allows a freedom that competes with the rigidity of pain.

Singing: Singing is the body's natural instrument. Singing out a song with a full complement of dynamics conveys feelings while requiring attention to the notes, lyrics, and interpretation, turning one's focus and attention away from pain. Music therapy offers a plethora of techniques for changing the perception of pain in patients from infants, to children, and through adulthood. Music therapy may provide coping strategies for both acute and chronic pain, and in randomized controlled trials has been found to be effective. The neuromatrix theory and tension release model help to explain the impact of music therapy, while musical processes facilitated through the therapeutic alliance can result in a potential decrease in pain perception. Music therapy is a safe, benign, and potentially effective integrative treatment that is indicated for many different kinds of pain and painful circumstances.

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Falling Out Of a Car Inspires a Good Story

by Janet Ruddock

Editor's note: Creative writing is one of the arts used by many people with pain to gain perspective on their lives and provide an outlet for their emotions. Here, facilitator Janet Ruddock shares how writing fits into her busy life.

ast week I fell out of the car. I wasn't driving and the car wasn't moving.

Still, falling out of a car is never a good thing. My husband and I had stopped for coffee. As I turned to leave the passenger seat, somehow my feet got caught.

Both knees hit the ground. With my feet bent backwards, I skidded along the pavement on my shins. Landing on my wrists saved me from falling flat on my face. Our first aid kit dealt with some nasty cuts and copious amounts of blood. Nothing broken, but I tore my new dress.

I expected to feel somewhat bruised and battered. Yet the next few days I functioned with amazing ease despite various stinging wounds. It was the calm before the storm. Chronic pain does not like trauma. My body was simply winding up for the aftershock.

Sure enough, almost a week after the fall I felt like I'd been hit by a truck. Having been down this road before, I knew the drill: carefully increase pain meds, take hot baths, rest but not too much, and exercise but not too much. Still the pain persisted and spread.

So, today I saw my doctor. He watched me maneuver gingerly down the hallway as I described my "minor mishap." He smiled. My mishaps are seldom minor. We didn't get too far testing my flexibility. I could barely move. Referred pain ran riot. My fibromyalgia is just plain unhappy with the whole affair. Overall I gave a fine impersonation of a robot.

If I was hoping for a quick fix, I was wrong. A good treatment plan and time will ultimately provide relief. Meanwhile, here I am sitting at the computer happily writing. I may be stiff as a board but I'm engaged in one of my greatest pleasures. My brain is up to the task, as are two of my best typing fingers. And that's all I really need.

When engaged in creative writing, I never lack for ideas. I write about what's happening in my life and I don't always write about pain. Pain just happens to be on my mind right now. I tend to write short stories, as sitting for long stretches is not a good idea for someone who is stiff and achy at the best of times. I often include humor, which is a great distraction when dealing with a topic like pain.

When things are running smoothly, I am inclined to do too much and miss my precious time at the computer. Pain tells me I need to slow down. Relaxing at the computer gets me off my feet. Writing even one page relieves my frustration at being inactive when limited by pain. Thus, I'm in a better frame of mind to deal with whatever pain feels it needs attention.

I love to write anytime but when pain flares up I'm grateful to be able to distract myself with some idea lurking in my head. But you don't need to fall out of a car to produce a good idea or the prolonged recovery time to write about it.

In fact, my advice is not to fall out of a car for any reason.





Letter to the Editor

Dear Penney and the ACPA,

I appreciated your Complementary Alternative Medicine coverage in the June issue of The Chronicle, as well as your perseverance over the years for our underdog cause!

I would like to add that there is a vast body of solid research evidence for the effectiveness of cognitive behavioral therapy (CBT) with pain. Gestalt, acceptance and commitment therapy (ACT), CBT, somatic experiencing, supportive psychotherapy, dialectical behavior therapy (DBT), hypnotherapy, family and group therapies have plenty to offer us in an arena where mind, emotions, autonomic nervous system, stress, pain, and social relationships interact. Mindfulness Based Psychotherapy is making use of the findings by investigating the effect of mindfulness on chronic pain.

In fact, the cutting edge of chronic pain treatment would seem to be brain sciences, which offer a new way of looking at and treating chronic pain as brain centered; fMRI research shows that it's real.

The National Institutes of Health studies show that one out of four Americans has a diagnosable mental illness. These often manifest as depression, anxiety, insomnia, or substance issues, all of which are especially common among those with chronic pain. Still, most people wait through 10 years of unnecessary suffering before seeking help out of fear of the ongoing stigma. So it would be a great service to all to help highlight psychotherapy as one aid for chronic pain.

I hope future articles could explore mind, body, chronic pain, and psychotherapy.

-Charles Horowitz, Ph.D.

ACPA Updates

Pet Rabbits Prove Therapeutic for Pain

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Bunnyboy meant so much to me that he became my first formal therapy bunny.

Today, as members of Bunnies in Baskets (AAT), my new bunny Muffin and I are visiting residents of rehabilitation centers, schools for handicapped children, and pediatric hospice patients.

We spent one day comforting the children in Sandy Hook, Newtown,

Connecticut, at the Children's Adventure Center. The director, who also has fibromyalgia, and I both agreed that watching Muffin's interaction with the children decreased our pain as well.

As new members of the Butterflies Program for Valley Hospital in Ridgewood, New Jersey, Muffin and I will have the opportunity to bring comfort to children suffering from the pain of cancer.

Comforting Warmth and Relaxation

Muffin and I visit several rehabilitation centers throughout the year. The positive effect she has on people recovering from major painful surgeries, or learning to live with chronic pain, is a joyous sight. On one visit, Muffin seemed to home in on the needs of a woman recently diagnosed with Reflex Sympathetic Dystrophy. This woman delighted in feeling the warmth of Muffin's soft body as she relaxed on her chest, saying "She is content because I am rubbing her belly."

On another day, Muffin and I went out on a therapy assignment on a cold, rainy day when my fibromyalgia pain was at its worst. A woman had just had a spinal cord stimulator implanted, but the smile that radiated across her face when Muffin cuddled in her neck was priceless. By the end of the two-hour visit, my happiness overshadowed any pain I was experiencing as I looked at the faces of these people, happy and content—even if only for a short time.

Companionship and Purpose

In addition to providing a few minutes of comfort and joy, therapy animals fit into in their owners' lives as someone new to love. Pets provide companionship, as well as a purpose in life, a reason to get out of bed, and perhaps a reason to go outside for a walk. When your pain is at its worst, and others in your life may find you difficult to live with, your pets are always able to listen and sympathize.

Nancy Laracy is a writer and advocate for the chronic pain community who is very involved with AAT. Learn more at www.nancylaracy.com.

Combined Federal Campaign

The American Chronic Pain Association has been accepted by the U.S. Office of Personnel Management for the inclusion in the fall 2013 Combined Federal Campaign as a member of Health & Medical Research Charities of America. If you work for the Federal Government and would like to designate the ACPA for a contribution, please use our CFC number 10549. This is only valid for CFC members.

The Art of Pain Management

CONTINUED FROM PAGE 1...

There are many forms of art and a wide variety of music that people with pain can make part of their daily activity. Even on days when you are too busy or too tired, you can still listen to music. Allow the music to gently replace any thought you might be having. Remember, we have one-track minds that can only focus on one thing at a time. So while you are concentrating on a great rock band or a wonderful symphony orchestra, you are not thinking about your pain. At least for a few minutes, you can reduce your sense of suffering.

The ACPA is launching a new project entitled the Art of Pain Management. We are excited to bring this collection of projects, personal reflections, and helpful hints to you. We are also excited to tell you about the PAIN Exhibit at www.painexhibit.org. We hope you enjoy this issue of The Chronicle as we explore art and music therapy for pain management.

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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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.

The Chronicle is published quarterly by the American Chronic Pain Association.

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

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