



CHRONICLE



The Art of Communication

by Penney Cowan, Executive Director, ACPA

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It would be great if we had an unlimited amount of time to explain to our health care professionals (HCP), family, and friends how our pain feels and how it affects our daily life. Too often, we spend a huge amount of time trying to tell others what our pain is like, trying desperately to find the right words so they will understand. What we want more than anything is for them to—just for an instant—feel our pain. We want them to understand the control it has over us. But no matter how good our adjectives, no matter how descriptive we are, they will never be able to feel our pain.

However, it is still important to sharpen your ability to communicate the impact the pain has on your life. These people need to know how

intense it can be and the limits it places on daily life, not to mention the control it ultimately has over everything we do and say. Communication is the thread that binds together your needs, treatments, expectations, and ultimately, your quality of life.

The American Chronic Pain Association understands that you must make your HCP understand your pain so that he or she can address your needs. You look to your health care professional to validate your pain and provide you with treatments that will be effective and efficient.

Communication is key to accomplishing any and all of this. Without it, you cannot move forward with your treatment plan.

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Communicating Around Barriers: What We Know, Say, and Do

by Erin Kelly

When you meet someone new, you form an impression of that person based on what you see and hear—but also influenced by your own personal biases. If you make the wrong assumptions about your new friend, it can be hard to accept information that contradicts your preconceived notions.

Living with chronic pain is very difficult for others to understand, and the things we do—and don't do—send messages about pain that can be confusing to friends and family. Personal biases and misguided assumptions about pain and disability can also interfere with open and honest communication. Recognizing the communication barriers that affect people with chronic pain can help you communicate better—with friends, strangers, or even your own doctor.

Appearances Can Be Deceiving

Most people have a mental picture of someone with pain that includes pajamas, unkempt hair, and a pinched, painful facial expression. But people with chronic pain don't usually fit that stereotype, which can cause others to doubt that they are hurting.

"Many people put extra effort into dressing and grooming when they go out—partly because it makes them feel better," says ACPA facilitator Deborah Daly. "It's a way to work on the problem from the outside in." And keeping up your appearance can make you feel more normal. "I always used to be well groomed, and well put together," says Catherine Cartwright, an ACPA facilitator from Vallejo, CA.



But looking good can backfire. "People don't realize they're seeing my best," explains Cartwright. "They think I am healthier than I feel." Cartwright counters this perception with the truth: "I tell them the reason I look so good is that I save up to look good." By this, she means that she will pay for the effort used to dress well by taking an extra nap, skipping other chores or activities, or feeling more pain.

Daly learned a surprising lesson about how physical appearance can hurt communication when she started using a motorized scooter to get around. "People communicate with me now completely differently than they did when I was walking," she says. "I get ignored, or they talk to me like I'm a child or mentally retarded," Daly explains. She also gets "shouters," who talk loudly because they think she won't understand. "I tell them, 'My ears are fine!'" Although she finds it amusing, she knows that it's not always a joking matter because people

might not take her seriously. "You have to be careful about getting your point across," Daly says.

Mistaken assumptions cause communication problems for all people, not only those with physical limitations. "I have a friend who is from Japan and speaks with a strong accent," Daly says. "It used to be that when we were out together people would ignore her and speak only to me. Since I started using the scooter, they ignore me and talk to her!"

Another factor that can confuse family and friends about the seriousness of pain is the type of medical treatments you use. "Sometimes people think you don't hurt very badly if you decide not to take strong pain medications or have surgery," Cartwright says. She was offered spinal fusion surgery to alleviate her pain, but decided that the risk was too great since she is African-American and at risk for keloid scarring.

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People think that if you won't try everything, then you must not hurt that bad.

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"I'd already had a different procedure that didn't work, and I could not guarantee what I would do if the pain got any worse," Cartwright says. She also watched a friend suffer through several failed surgeries and eventually die from a complication. Although there are plenty of valid reasons to refuse surgery or narcotic pain medications, it's difficult for others to understand if they are not the ones doing the research and making the decision, Cartwright says. "People think that if you won't try everything, then you must not hurt that bad," she explains.

Accepting Doubt and Disbelief

Because you can't see another person's pain, it can be difficult to believe that it exists. Even spouses and close friends who want to understand what it's like are troubled by doubts.

"Almost everyone has problems with family members because of pain," says Cartwright, who has led ACPA support groups for three years. Her own marriage ended after she became disabled from a back injury. She tells of a young couple who attended her group to learn about the wife's pain: "The husband wanted to help, but he was critical, saying, 'She can't do this, she can't do that.' It was obvious he didn't really understand how she felt." Later, the husband was also injured and became more sympathetic.

Daly, who leads support groups in San Diego, CA, has known a lot of people who feel they don't get the right support from their spouses. "They try to explain over and over again, and it gets very frustrating," Daly says.

"The techniques we learn in the group help us to accept the fact that people don't understand completely,"

Cartwright says. "We learn not to expect it, and that it doesn't mean that they don't love us." Having a support group of people who really do understand is a relief. "It's wonderful to have people you can really connect with and not have to explain yourself," Cartwright says.

For some families, culture plays a role in how easily they recognize and accept pain as a disability. Although Cartwright only speaks from her own experience, she thinks that African-Americans' history of perseverance through slavery and hard physical labor might make it harder for them to understand a chronic pain diagnosis. "African-American women have always had to keep moving and working regardless of how they felt," Cartwright explains. "If you say you have pain, the response is 'Who doesn't?' I don't think my family really 'gets' what's going on with me."

A few unlucky spouses do get a taste of what living with pain is like. Cheryl Neuenschwander, an ACPA facilitator who recently started support groups in Tracy and Stockton, CA, says her husband has always been good at reading her pain level from her posture and the tone of her voice and automatically takes over the tasks that she is not up to doing.

But she says he really became a strong advocate for her after he was injured at work. "He was down for a month with a back injury," Neuenschwander explains, "and he went through the same things we do—hurt, self-pity, and frustration at not being able to do things."

"On one of his whiny days I told him, 'I really do understand.' He looked at me and said, 'Yes, you do.' He finally

realized what I'd been dealing with for 20 years," Neuenschwander says. After he recovered, Neuenschwander noticed him defending her more readily, even going out of his way to challenge a friend who made a dismissive comment about her pain.

Fighting Stereotypes and Bias

In addition to the cues people take from your actions, people bring their own biases to relationships. Many situations that can arise as a result of chronic pain carry their own negative stereotypes. People on public assistance are thought to be lazy; people who come to the doctor with pain must be drug-seeking addicts; people with work injuries are probably scamming their insurance companies; and people who have pain with no obvious cause must want attention. If people believe these stereotypes—even a little bit—honest communication is more difficult.

Cartwright had to fight stereotypes about work injuries after she injured her back on the job. She had recently completed her education to be a drug and alcohol counselor and was entering her working prime in a career she loved. "The insurers and doctors seemed to downplay what was wrong with me," Cartwright says. "They always tried to say my symptoms were from something else."

Her strong sense of self-worth and her background in human services helped her advocate for herself despite these prejudices. "I knew what was right," she says. "The year my son graduated from high school, I was working two and a half jobs and taking nine units at school with a 4.0 grade point average. Is that lazy?" she says.

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Communicating Around Barriers

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Daly saw an ugly side of prejudice from the medical community when she went to the emergency room with problems from a changed pain medication. “The chart didn’t explain the whole situation, it just said I had morphine withdrawal,” Daly says. A nurse who treated her assumed she was a drug abuser and that assumption tainted every interaction between them. “The way that nurse treated me was incredibly insulting,” Daly says. The doctor, who knew the whole story, was much kinder. “The doctor treated me with respect,” Daly says. “When the nurse saw that, she changed her attitude.”

A former medical assistant, Daly believes the medical community could improve communication by learning to not bring personal biases about pain to interactions with patients.

“When I interview a new doctor, question number one is always, ‘Do you know anything about my condition?’” Daly has reflex sympathetic dystrophy syndrome (RSD), a rare condition unknown to some physicians. “I can tell in a few minutes whether or not a doctor is going to be helpful,” she says. “If they’re familiar with it, or are willing to learn, they’ll be sympathetic and engaging. If not, they tend to shut down. Sometimes doctors act like if they don’t know about something, it’s not real,” Daly explains.

Many chronic pain conditions are controversial diagnoses. “A few years ago, doctors were telling people that fibromyalgia was all in their heads,” Daly points out. A physician with doubts about your problem will likely have difficulty taking what you say seriously. Even the tools that doctors are taught to use sometimes show how traditional medical perspectives are different from

what’s important to someone with chronic pain. “The pain chart that doctors give you to rate your level of pain from 1 to 10 just does not work,” Cartwright says. “What number means ‘lying in bed wanting to die?’” she asks.

The ACPA’s *Quality of Life Scale* focuses on how pain changes your life rather than pain intensity. Sharing the *Quality of Life Scale* with your doctor is a good way to help him or her understand your perspective and start to break through biases for better communication about your health.

Using Humor

Daly believes humor is a great way to “break the ice” when communication is difficult. For example, when she is on her scooter she sometimes meets able-bodied people using an accessible bathroom stall or changing room and they’re embarrassed that they made her wait. “I usually make a joke that lets them know I’m fine. I try to put them at ease, and they realize I’m just a normal person,” Daly says.

Neuenschwander also relies on humor, especially when dealing with doctors. “You need to ask questions and stick up for yourself with your doctor, but sometimes when doctors are overscheduled and rushing to get through the appointment, they don’t really welcome discussion,” she points out. “Sometimes joking can trip them up for a moment, and get their attention.”

And because nobody likes to be told their methods aren’t working, Neuenschwander recommends a positive approach when questioning a treatment. “Ask if there’s something you could do differently, like exercise, or acupuncture, or a less invasive treatment,” she says. “Usually, they become intrigued. It’s refreshing to have someone take an interest in their

own health; a lot of people don’t want to take that responsibility.”

But a sense of humor about the situation doesn’t come naturally for everyone. Cartwright admits she’s struggled over the years to control her anger about chronic pain. “My life changed 360 degrees after I got injured,” she says. “It took me eight and a half years to piece together some kind of life. I had to grieve for my old life before I could push through to the other side.”

The resources she found through the ACPA helped her, as did her pastor and her faith in God. She also realized she needed to work on her attitude. “I was angry, but I realized that lashing out at people wasn’t going to help. Now I know that I need to channel my energy in a positive direction.” Cartwright says the ACPA was part of that positive change, helping her learn better ways to advocate for herself and eventually to start a support group.

One tool that Cartwright uses to control her attitude is the connection between her mind, body, and spirit. “Your mind and spirit, or soul, are as much a part of you as your physical body,” she says. When one part is weak, the other parts can help compensate. “If your body is hurting, you need to call on the spiritual and mental parts to elevate the physical part,” says Cartwright. “There are days when I need to be out, even if physically I don’t want to do a thing, because I need to feed my spirit.”

Communicating with another human being is one of the hardest—and most important—tasks we undertake. Recognizing the cues you send and understanding the biases that others might bring can help you become an expert at expressing yourself to your family, friends, and colleagues.

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Talking About Pain

Recently, ACPA expanded its range of tools that help people with pain and healthcare professionals communicate. These tools use pictures and graphics to overcome language and literacy barriers.

Three logs help you track, understand, and assess your pain.

- * **Living Better with Pain Log:** to track pain triggers and progress in managing pain.
- * **The Fibro Log:** to track how Fibromyalgia pain is affected by everyday activities, feelings, and circumstances
- * **Quality of Life Function Scale:** to supplement typical pain assessment scales

Two tools help you understand instructions from healthcare providers.

- * **CARE Card:** for communicating prescription instructions
- * **Follow-up Sheet:** for communicating instructions about tests, restrictions, diet, appointments, and treatments following a provider visit.

These are all available on our ACPA Web site, www.theacpa.org.

A Quick Scan Reveals Progress

You can use these tools to help you observe and track when and where your pain is better and worse and how it affects your daily life. This will give you a record that you can share with your doctor.

These same tools can help you share the facts of your condition with family without feeling like you are whining.

The logs are easy to complete with just a circle or check mark and can be scanned quickly.

Preparing for a Doctor's Visit

When we go to the doctor we sometimes have the expectation that this visit will be the one to take away the pain. A more helpful mindset is deciding what you realistically want to come away with—i.e., better pain management skills, more focus, fewer side effects from medication, or less fatigue.

Along with bringing the completed logs, make a list that includes:

- * New symptoms and reoccurring symptoms,
- * The medications you take, including over-the-counter meds and supplements,
- * Methods of relief tried, such as heat, massage, or exercise, and what the results were, and
- * Changes in your daily level of functioning, mood, appetite, or sleep.

When visiting your healthcare provider:

- * Become part of the treatment team,
- * Take an active role in the recovery process,
- * Work together to find ways to best manage your pain,
- * Bring someone with you to help remember what is said.
- * Stick to the point and avoid repeating information the doctor has already heard.

Your goal is to reduce your sense of suffering and get back to doing the things that matter most.

Communicating with the Family

When pain is not properly managed, it may make you feel hopeless, depressed, angry, and/or confused. When you hold in negative emotions, you carry around an extra burden, causing tension and stress that actually increases your pain and depletes your energy.

When pain forces you to change in your role within the household, you may feel guilty; you can no longer provide for your loved ones or handle daily chores. People with pain often feel they have no control over their lives.

Your spouse and other family members are experiencing these same feelings. They are also struggling with confusion, guilt, and sadness—they just don't feel the pain. By acknowledging that you all share the emotional impact of chronic pain, you can work together to bring these negative feelings out in the open.

Sharing Your Feelings with Friends

When you have learned how to manage your pain and established yourself as a healthy person, you want to continue to project this image. On a bad day, you may not want to fall back into the role of a patient by saying, "I'm not feeling well today." But if you say nothing, your distant attitude and lack of enthusiasm may be interpreted by your friends as a personal rejection.

You need to devise a means to cope with painful days and communicate with others that you are glad to be with them, but are just having a bad day physically.

Though you are managing your pain and others may see you as well, there are times when you will not be able to do certain tasks. Remember, asking for help is one of your basic rights.

Adapted from Chapter 12 of *From Patient to Person: First Steps handbook (Chapter 12)* and *Staying Well: Advanced Pain Management for ACPA Members*. For more, read "Improving Communications with your Health Care Provider," *Fall 2007 Chronicle*, page 6.

Psychological Addiction with Opioid Use

by Sarah McDowell and Grant Kuns

Opioids are a class of prescription drugs commonly used for their analgesic, or pain relieving effects. Some common names of prescription opioids include: morphine, oxycodone, hydrocodone, and methadone. Opioids act on the brain and the body by attaching to specific proteins called opioid receptors. These receptors can be found in the brain, GI tract, and spinal cord. When the receptors are occupied by these medications the perception of pain is blocked and pain tolerance is increased. This is why they are an effective, short-term medical solution for severe pain, such as that experienced after surgery.

Opioids are also advantageous for treatment of various types of chronic pain because there is not an upper limit to dosing. Pain relief is possible as long as side effects are tolerated and adverse events do not occur. Common side effects can include nausea, constipation, sedation, and respiratory depression.

Because of the positive effects people experience when they take opioids, they can sometimes abuse these medications. Opioid drugs can induce euphoria, a sense of happiness and well-being, by affecting the brain regions that process what we feel as pleasure. This feeling is often intensified for those who abuse opioids and administer them by non-recommended routes.

Beneficial Medication or Dangerous Drug?

Psychological addiction does not occur in everyone who takes an opioid. If used correctly, opioids are excellent medications for moderate to severe pain. Problems with serious side effects are infrequent. However, some people develop psychological addiction and/or begin to use these medications incorrectly. When this occurs, the risk for harm outweighs the potential benefits of opioids, and the patient's previously effective medication turns into a potentially dangerous drug.

Psychological addiction or incorrect use of opioids can lead to many serious consequences including respiratory depression and death. The Center for Disease Control and Prevention (CDC) recently reported that the death rate for opioid overdoses in the United States climbed from 4,000 deaths in 1999 to over 13,000 in 2006. That is more than a 300 percent increase in just seven years!

According to the American Pain Society, addiction is a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its

development and manifestations. It is characterized by behaviors that include:

- * Impaired control over drug use
- * Compulsive use
- * Continued use despite harm and/or
- * Cravings

Addiction is what happens when a drug stops being a means to an end, and becomes an end in itself. When taking the drug becomes more important than controlling the pain, that's addiction.



Addiction reveals itself as a set of behaviors that are the signature signs. These include loss of control over drug use, compulsive use, continued use despite harmful effects and cravings that are so powerful that the user is willing to take dangerous actions, risk jobs and relationships, or even commit crimes in order to acquire and use the drug.

If you, or someone you know, are addicted to opioids, it is never too late to seek help. There are many support groups and Web sites for helping individuals fight their addictive habits. For more information about addiction or how to join these support groups, you can call or visit:

- * www.recoveryconnection.org (1-800-993-3869)
- * www.projectknow.com (1-866-531-8636)
- * www.prescriptiondrugaddiction.com
- * www.nida.nih.gov/Researchreports/Prescription/

Note: The authors are Pharm D Candidates, Duquesne University, Pittsburgh, PA. Student articles have been reviewed by their professors for accuracy.

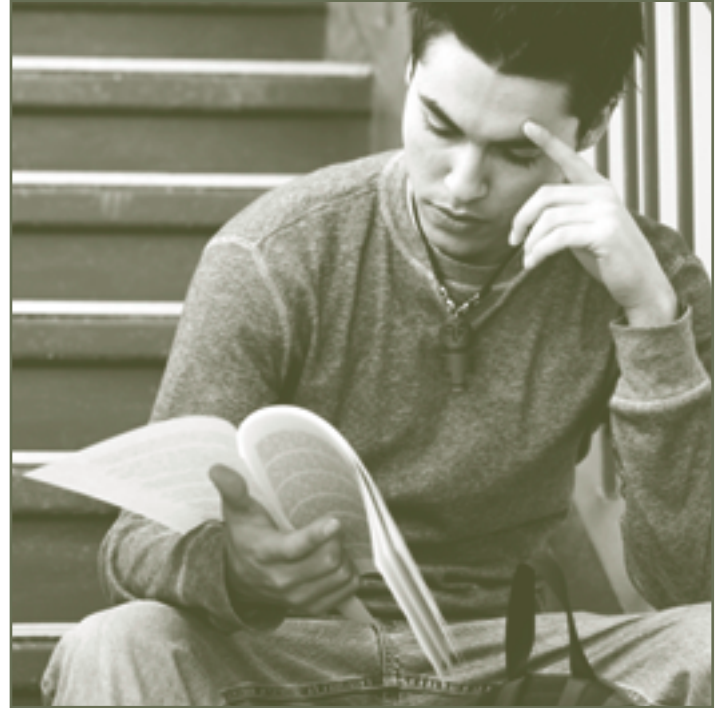
Study Reviews Controlled Substance Management (Opioid) Agreements

Controlled substance management agreements (also known as CSAs, contracts, or opioid agreements) are widely used by pain specialist physicians. Mark R. Collen recently surveyed and analyzed 41 controlled substance medication management agreements available on the Internet from physicians in private practice. The results were published in the *Journal of Pain & Palliative Care Pharmacotherapy*, Vol. 23(4), 2009 (www.informahealthcare.com/ppc).

“I chose to do the survey analysis because one had not been done in ten years and agreements from private practice physicians were never analyzed. It was important to add to the literature and see what clinicians from across the U.S. were using in their practices,” said Collen, creator and coordinator of the Pain Exhibit (www.painexhibit.com). He discovered the online agreements while doing research for another article published in the *Journal of Law, Medicine & Ethics*, called “Opioid contracts and random drug testing for people with chronic pain—think twice.” Collen describes a CSA as a written agreement between doctor and a person taking opioids or other controlled substances as part of treatment. It explains directives that the person with pain must comply with under this doctor’s care. “Although the intent of a CSA is to improve care, their efficacy remains unproven,” he states.

Collen analyzed these 41 qualified agreements—the shortest was 425 words while the longest was 3331 words (between one and eight pages). His analysis looked at the contracts’ content; practice-specific information, such as refill protocol and treatment goals; educational statements such as adverse effects and drug interactions; directive/instructive statements such as prohibiting alcohol while taking medication; and violation emphasis, which explains rule violations and their consequences.

The top two refill protocol/rules were in 98% of agreements: “Use only one doctor for prescribing controlled substances” and “No early refills.” The next most common rules restricted people to one pharmacy and required them to keep their appointments. In addition, 93% of agreements required people with pain to submit to random drug screens and the same percentage allowed the doctor to communicate about the person with outsiders such as insurance firms, law enforcement, other health care providers, and family members.



Read and understand all contracts before signing anything.

A focus on “abusing/misusing licit/illicit drugs” was in 90% of CSAs. The top violation cited was “failure or refusal of random drug screen” (56%).

It is important that people with pain have a clear understanding of what these agreements with physicians are and what they mean for their treatment. If you feel compelled to sign them and don’t read them carefully, you may be surprised when you unwittingly violate the terms of your agreement and are dismissed from the care of your provider. (For more about CSAs, read “The Legal Side of Pain,” *ACPA Chronicle*, Spring 2007, page 5.)

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Hypnosis for Chronic Pain Management: New Evidence for an Old Treatment

by Mark P. Jensen, Ph.D.

Although it is possible to find descriptions of people using hypnosis and hypnotic-like phenomenon to treat medical conditions throughout history (including the “dream temples” of ancient Egypt and the “sleep temples” of ancient Greece), most authors agree that the origins of the modern scientific examination of medical hypnosis began with Anton Mesmer (1734-1815).

Mesmer was a physician practicing in Paris in the late 1700s. He believed that bodily tissues held magnetic energy, and that this energy could be directed, using magnets, to ease symptoms and heal disease. He also believed that some people inherently had more magnetic energy (animal magnetism) than others, and could be very effective healers if they focused and directed this energy. His treatment involved having patients sit around a baquet (a tub filled with water and iron fillings) and hold on to iron rods through which healing magnetic energy, guided by him, was flowed through the patient. When treated in this way, his patients would go into convulsions and then be taken to a recovery room. As they recovered from the experience, many reported being “cured” of their disease or symptoms.

Mesmer’s treatments were so effective and he became so popular that he soon attracted the attention of the authorities. King Louis XVI appointed a commission (which included Benjamin Franklin who was living in Paris at the time) to investigate Mesmer’s practice and theory of animal magnetism. The commission determined, through careful experimentation, that the theory was incorrect. Mesmer’s profound results, they concluded, were “only” due to the engagement of the imagination of his patients. As a result of their report, Mesmer was discredited, and subsequently left Paris in disgrace.

Though the commission acknowledged that engaging a person’s imagination could effectively reduce his or her symptoms and that this effect should be examined further, the discredited theory and Mesmer’s disgrace made many in the mainstream hesitant to use or study mesmerism. Interest in mesmerism therefore declined substantially over the next few decades.

There was an increase in the popularity of mesmerism in the mid-1800s when it was shown to be an effective anesthetic for surgery by an English surgeon working in Calcutta, India. However, both ether and chloroform were discovered soon after this and found to be so effective that interest in mesmerism as a surgical anesthetic died out. Mesmerism came to be called hypnosis (a term first coined by an English physician in the 1840s) to separate it from the negative history associated with mesmerism.

How the Brain Experiences Pain

Currently, interest in hypnosis for pain management is again on the rise. This increased interest is likely due to three converging factors.

First, with the technological advances in our ability to understand brain activity, we now know much more about the importance of the brain in our experience of pain. We now know, for example, that there is no “pain center” in the brain, but that people hurt when multiple areas of the brain are active; these areas together are sometimes referred to as the pain matrix. Also, although input from outside of the brain can and often does play a role in our experience of pain, it is the activity in the brain that is most closely linked to our experience of pain. All pain is in our heads; when activity in the pain matrix changes, our experience of pain changes.

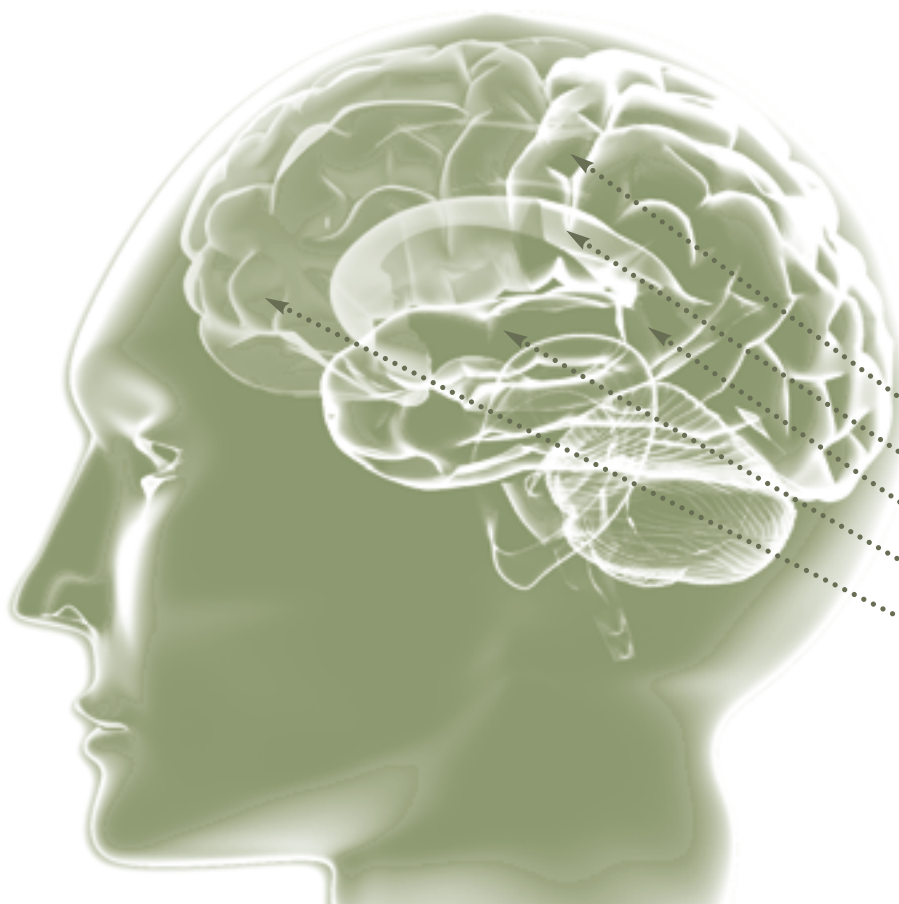
Second, scientists can now observe the direct effects of hypnosis on brain activity, which affects all of those areas and structures of the pain matrix. This includes the thalamus, a structure which can be viewed as a sort of relay or central station. About 90 percent of the information from outside of the brain passes through the thalamus to get into the brain.

The pain matrix also includes the sensory cortex—the area of the brain that is active when we feel sensations. A third area of the brain involved in our experience of pain is the anterior cingulate cortex, which evidence indicates is involved with processing information about how pain makes us feel. This area is more active when we are very upset or distressed about pain and sensations. The insula is an area of the brain that becomes active when something is perceived to be wrong about our body—when we need food and become hungry, are short of oxygen and need to take a breath, or when we perceive physical damage and feel the need to protect ourselves. This area also becomes active when the body is stimulated and we feel pain.

Giving Meaning to Sensations

Finally, the prefrontal cortex is the area of the brain that is likely involved in the meaning we give to our sensations and experiences. Are they safe? Dangerous? Is it a passing sensation that has little meaning to our future and overall well-being or is it a sensation that means something is drastically wrong?

These areas of the brain can also influence each other. So when we think that pain may indicate something is broken or breaking (activity in the prefrontal cortex), the pain can increase in



Multiple areas of the brain are involved in experiencing pain, including the

- sensory cortex,
- anterior cingulate cortex,
- insula,
- thalamus, and
- prefrontal cortex.

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intensity (activity in the sensory cortex) or can worry us more (activity in the anterior cingulate cortex). This new understanding about the brain does not mean that pain is “made up” or not real, but it does explain how the same level of stimulation can be felt differently by different people. Importantly, it also can explain why something like hypnosis, which affects the brain, can also have profound effects on our experience of pain.

The third factor that has led to an increased interest in hypnosis for pain management is that controlled clinical trials show that hypnosis is consistently more effective than no treatment (“standard care”), and is either “more effective” or “as effective” as other effective pain treatments. Thus, hypnosis has been proven to be something more than just a placebo.

Suggestions to Feel Differently

Hypnosis is not that complicated. Simply stated, it can be defined as an “induction” followed by a suggestion (or set of suggestions). The induction usually consists of an invitation to focus one’s attention on the therapists’ voice, a point of light, or a mark on a wall. This focused awareness or attention has been shown to make people more receptive to suggestions to change their experience. An induction can take several seconds or up to 10 minutes or longer, depending upon the clinician’s usual practice and the hypnotic subject’s response. When used to treat chronic pain, this induction is then followed by suggestions for the client to feel pain sensations differently, to be less bothered by the sensations, to think differently about pain, to be better able to ignore pain, or some combination of these and other suggestions.

A hypnotic treatment session can end with suggestions that any benefit or relief obtained during the session will last beyond the session—and in many people it does, sometimes for hours or days. It is also suggested that the client will be able to enter this state of comfort easily in the future and that when he or she does so, the relief and comfort will again last for a period of time.

In our studies, we have made a number of observations about this approach that might interest the readers of the *Chronicle*. First, the response to the treatment is variable. Some people report that they got no benefit from treatment, although this is very rare. Some people report that they have a profound and life-changing response to treatment—perhaps the pain has largely disappeared, or has become so insignificant that it might as well have disappeared. This response is also rare. Most report some benefit—not a “cure”—but reductions in their daily pain.

Many of the participants in our hypnosis studies also report “side effects” of the hypnosis treatment, including an increase in the quality of their sleep and an overall increase in their sense of relaxation and well-being.

If you are interested in exploring whether and how you might benefit from learning self-hypnosis strategies, it is important to choose the therapist you work with very carefully. There is no state license required to practice “hypnotherapy,” so anyone can advertise and recruit potential clients.

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Part of a Comprehensive Pain Program

Many professionals with knowledge about hypnosis know that “hypnosis” should rarely be offered by itself. It should be offered as a part of a complete pain treatment program, that might (for individuals treated by licensed clinical psychologists) also include cognitive behavioral therapy. Or it might be offered as part of biomedical treatment program (for individuals treated by a licensed physician) that involves the management of appropriate medications and a supervised physical therapy program. Anyone offering hypnosis should have appropriate training in this approach and also have an advanced degree (for example, a Ph.D. or M.D.) and be able to offer other appropriate treatments in addition to hypnosis.

Although there is no license required to practice hypnosis, there are four reputable organizations in the U.S. whose members are vetted to have adequate credentials and training for using hypnosis in their clinical practice:

- * The Society for Clinical and Experimental Hypnosis (www.sceh.us)
- * The American Association of Clinical Hypnosis (www.asch.net)
- * The Milton Erickson Foundation (www.erickson-foundation.org)
- * Division 30 of the American Psychological Association (www.apa.org/divisions/div30/homepage.html)

These organizations have combined efforts to create a single Web site for individuals seeking referrals for hypnosis treatment at www.societiesofhypnosis.com.

Hypnosis is not magic; it is an approach that has been demonstrated to be effective for chronic pain management and its effects can be seen on measures of activity in the brain areas involved in the experience of pain. Although not everyone benefits from training in the use of self-hypnosis for chronic pain management, many do. It might be something for individuals who want another tool to better manage their pain to consider.

Mark P. Jensen, Ph.D., is a Professor and Vice Chair for Research in the Department of Rehabilitation Medicine, University of Washington School of Medicine. His research program focuses on the development and evaluation of effective psychological treatments for chronic pain.



The Art of Communication

CONTINUED FROM PAGE 1...

You are on the Team

You need to work directly with your HCP in the same way a football team plays. Your primary care physician is your coach, guiding you forward through the obstacles. There are other HCPs playing special teams, but you are the quarterback. You are involved in every play. If you do not understand what the coach is telling you, it is impossible for you and your team to reach the goal line. Everyone has to work together to achieve optimal pain management and communication is essential for this well-organized team approach to work.

Unfortunately, we usually have a limited of time to talk with our “coach” and other HCPs, so you need to make every moment count. For that reason, the ACPA has developed a set of communication tools for people with pain.

Use the Pain Logs

We identified some of the common issues that a person with pain faces and developed simple graphical images to aid in discussions. The *Pain Log* and *Quality of Life* sheet use pictures to help you explain to the doctor how your pain feels and the impact it has on your daily life. The Follow-Up sheet will provide a simple overview of what was discussed, recommend, and prescribed for you during your doctor’s visit. We also have the Care Card to help you understand how to take medications. Those of you with fibromyalgia can use the Fibro-Log to explain to your HCP what happens in your daily life and reveal the connections between different activities you do and your pain level. All these tools are further described on [page 5](#) and can be downloaded from the ACPA Web site. (www.theacpa.org/people/resources.asp)

You can read more about ways to improve your interactions between HCPs, family, and friends throughout this issue. Good luck and keep those lines of communications open.

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Children, Chronic Pain, and the Internet

by Tonya M. Palermo, PhD, Oregon Health & Science University

Children and adolescents report severe chronic pain as frequently as adults, with 8 percent reporting significant disability and distress related to their pain (Perquin, et al., 2000; Stanford, et al., 2008). However, children and adolescents experience more problems gaining access to specialized pain care than do adults, given the low number of dedicated pediatric chronic pain programs in the U.S. and other countries (Peng, et al., 2007). Despite emerging data supporting the efficacy of psychological treatment for pediatric chronic pain management (Palermo, et al., in press), psychological treatments are even less likely to be received by youth with chronic pain compared to medication and other services.

For example, in one study of health service patterns among youth with chronic pain, while the majority of youth had used medications for pain, only 2.8 percent of children and adolescents received any psychological treatment services (Perquin, et al., 2001).

Multiple barriers exist when children and families try to get treatment services for pediatric chronic pain management:

- * In rural areas, some families may encounter a lack of trained specialty clinicians nearby and would have to travel long distances to major treatment centers.
- * Some face expensive treatments and insurance limitations.
- * Some have difficulty following therapy recommendations for their pain management, which often include recommendations for psychological treatment.

Seeking New Approaches

Recognition of these problems and barriers to access has led to the consideration of alternative ways to provide psychological treatments. A variety of innovative approaches have been tried over the years to provide psychological treatments outside the context of the clinic. Previously, self-help books have been used. More recently, as the use of interactive and communication technologies (e.g., Internet, personal computers, and voice recognition systems) has expanded, these technologies have been incorporated into approaches to improve or enable health and health care.

Today, using the Internet to deliver health and mental health treatment is a rapidly growing technique and it is clear that Internet delivery of interventions will play a major role in future health care. Examples of successful Internet-delivered psychological treatments are evident for many other health problems (e.g., obesity and tinnitus). Work on Internet-delivered treatments is just developing in pediatric chronic pain.



The Internet is an ideal medium to provide psychological treatments because many children and parents are familiar with this mode of communication, use the Internet regularly, and frequently search for health information online.

Internet for Health Research

A recent survey by the Pew Internet and American Life Project (2007) indicated that the majority of parents of youth (94 percent) and youth themselves (93 percent) use the Internet almost daily and 75 percent of American households now have broadband Internet access. Additionally, the rate of home broadband access increased dramatically among rural, lower income, and ethnic minority families in the past two years, and most Americans have access through work, school, or public libraries (Pew, 2007).

Health information is cited as the primary information accessed online (Powell, et al., 2005), and parents report using the Internet frequently to obtain information about their children's health (D'Alessandro et al., 2004).

Another advantage of the Internet is that it increases flexibility in treatment delivery. Many of the skills that are useful in pediatric chronic pain management rely on self management and practicing strategies in the home environment and the Internet offers a flexible way to increase skills practice. An Internet program can also be personalized and tailored to the needs of the patient, and can be used to provide social support.

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Children, Chronic Pain, and the Internet CONTINUED FROM PAGE 11...

Teaching Coping Skills

Recently, we completed development and evaluation of an Internet intervention to deliver psychological treatment to youth with chronic pain and their parents. This program, Web-based Management of Adolescent Pain (Web-MAP), was designed to provide cognitive and behavioral strategies to adolescents and their parents to reduce chronic pain and improve adolescents' ability to function in their normal daily lives (Long & Palermo, 2009; Palermo, et al., 2009). Many of the core strategies taught to children in psychological treatment are similar to the kinds of coping skills taught to adults (such as relaxation strategies, different ways of thinking, etc).

However, one difference in pediatrics is that it is also helpful to intervene directly with parents. Parents can learn strategies to more effectively communicate about pain with their child, to better support their child's pain management efforts, and to encourage participation in therapies and attendance at school. Therefore, we designed our Internet intervention to have treatment modules to teach skills to both parents and youth.

We conducted a randomized controlled trial of the Web-MAP intervention at our pain center with 48 youth with chronic pain (ages 11-17 years) and their parents. All youth were receiving specialized pain care and were randomized to either continue with their pain care only (wait-list control group) or to receive the Internet intervention in addition to their pain care.

Adolescents and their parents spent 8 to 10 weeks logging onto the Web program to use treatment modules,

view video clips of peers and parents dealing with chronic pain, and complete skills practice. Our results were reported in the November 2009 issue of *Pain* (Palermo, et al., 2009).

Change in Pain and Function

We found that more adolescents in families that received the Internet intervention experienced clinically significant reduction in pain from pre to post-treatment compared to adolescents in the wait-list control group. In addition, youth receiving the Web-MAP intervention demonstrated significant improvements in their physical functioning (e.g., ability to attend school, play sports, etc.) compared to youth in the wait-list control group. Future studies are planned to extend and replicate these findings in a larger, more diverse sample drawn from multiple medical centers (multicenter clinical trial).

Our preliminary findings are promising in demonstrating the potential utility of the Internet for treatment delivery. Children and adolescents with chronic pain represent an important population who might benefit from this innovative approach to treatment delivery. Over the next few years, as Internet programs continue to be tested and become available to the public, options for chronic pain treatment will be greatly expanded for youth and their parents.

Tonya M. Palermo, Ph.D. is Associate Professor and Chief, Division of Clinical Research in Pain and Regional Anesthesia, Anesthesiology & Perioperative Medicine at the Oregon Health & Science University.

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ACPA Update

Thank You!

Welcome to our new groups and facilitators.

Susan Suddoth
Springville, AL

Jerry Abrahamson
Desert Hills, AZ

Jennifer Starbuck
Stockton, CA

Cheryl Neuenschwander
Tracy, CA

Colleen Sanchez
Yucaipa, CA

Melisa D. Andrewjeski
Winder, GA

Katherine Fogg
Westfield, MA

Tony Moffitt
Niles, MI

Anita Herring
Rochester, MN

Shana Hayes
Grand Forks, ND

Ti Meehan
Rochester, NY

We are pleased to share the news that the ACPA satellite media tour, “Making Sense of Pain Medicine Confusion,” held on September 16, 2009, reached an audience of more than 4 million people.

The video and audio program featured Penney Cowan, executive director and founder of ACPA and David Provenzano, M.D., president of the ACPA board of directors. Dr. Provenzano is Executive Medical Director of the Ohio Valley General Hospital Institute for Pain Diagnostics and Care, in Pittsburgh, PA.

“The media outreach was a way to get the word out about the truths and myths of pain medicine use. We talked about the proper use of opioids, their benefits, and their side effects. We also tried to dispel some of the misunderstandings that people have about drug use,” said Cowan.

“For people with chronic pain, medication doesn’t produce euphoria, it allows them to function. Medication won’t solve all their problems, or even take away all the pain, but it does help reduce the suffering.”

The program was shown on 132 television stations, including national, regional, and local shows—news/talk and public affairs community programming. In addition, 25 radio stations and seven Web sites picked up the story.

Tribute

IN HONOR OF
DR. BARB MARKWAY
JEFFERSON CITY, MO
Given by Carol Gingrich

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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Thank you to these corporations for grants that enabled ACPA to fund special projects.

Pfizer for Fibromyalgia education campaign

Medtronic Foundation for redesign of the Web page

Forest Laboratories for the Fibromyalgia Web-based interactive person

King for support of Consumer Guide

Medtronic for Understanding Medical Devices DVD Web Cast

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.



Board Member Profile: Michael Gillis

This is part of a series of articles intended to give readers more insight into the interests and contributions of ACPA board members.

Michael Gillis, MBA, is the Associate Director for Administration of the Clinical and Translational Science Center at the University of California, Davis.

He joined the ACPA board two years ago, nominated by Dan Galia. "I've known Dan for several years and he felt it would be a good fit for me and the board," Gillis said. "I'm happy to be able to contribute what I can. It's important to have a broad range of skills and representation on the board." Gillis provides administrative management for all aspects of the Clinical and Translational Science Center, which works to improve the way biomedical research is conducted across the country, reduce the time it takes for laboratory discoveries to become treatments for patients, and engage communities in clinical research efforts.

"We are about bringing researchers together to encourage collaboration among investigators," Gillis said. "We try to break down the barriers to find common themes, identifying areas where they can work together."

Sometimes this is as simple as getting investigators from different disciplines to talk to each other. "We know there is a lot of overlap in research goals and

techniques. We provide seminars and sessions where they can discover these commonalities," he said. "The center supports translational activities; these involve taking a research program from one discipline and finding ways for it to relate to another."

The Center is a member of the Clinical and Translational Science Awards consortium, 46 medical research institutions that work to energize the discipline of clinical and translational science.

"Working together, these institutions can provide greater access to patient populations for researchers to recruit and study and enhance the efficiency and quality of clinical and translational research, recruitment, and studies," he said.

Gillis hopes these collaborations can expedite the research and discovery process, condensing the time from bench to bedside. "We hope to spur innovation, while still making sure clinical trials are safe, ethical, and effective," Gillis continued.

Mr. Gillis completed his undergraduate degree at the University of California, Davis and earned a Master in Business Administration from Saint Mary's College of California.

He appreciates the way ACPA advocates for people with chronic pain, serving as a focal point for disseminating reliable information on managing pain,

medical advances, ongoing research, and legislation. "It is important that people with pain have a common understanding and a common voice to respond to these issues. ACPA can be that voice," he said.

The collaborative work that ACPA does is similar to Gillis's efforts at the Clinical and Translational Science Center. Both organizations are forging bonds among researchers, the community, caregivers, sponsors, and institutions, all for the benefit of people with chronic pain or other conditions.

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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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