



THE PHANTOM MENACE II

FIGHTING THE PHANTOMS



by Doug Smith, MD, ACA Medical Director

“Pain is inevitable, but misery is optional,” says Dee Malchow, RN, describing her own battle with phantom pain. While we may not have a choice but to live with phantom pain, it need not dictate our attitudes, behaviors or quality of life.

The first of our “Phantom Menace” columns explained the qualities that distinguish phantom sensation from phantom pain and the difficulties we have at times describing and measuring these feelings. While both conditions are present to varying degrees for most people with limb loss and may not be avoidable, Dee Malchow notes that individuals can empower themselves to overcome, rather than be overcome, by phantom pain.

In this article, we will discuss medications, nutritional supplements and the importance of a positive mental attitude in fighting the phantoms. The next column will focus on physical modalities, nerve stimulation, ultrasound, massage, relaxation and other helpful techniques.

Once we’ve determined whether we’re dealing with phantom sensation or phantom pain - or both - it’s time to embark on a course of treatment. As a surgeon, I regret to say that surgery has

not been effective in treating phantom pain. While surgery can be beneficial in dealing with mechanical forms of pain, such as a bone spur or a neuroma, surgery is not recommended for phantom problems.

In looking at the nonsurgical options for fighting the phantoms, we frequently turn to medication as the first line in treating pain. A variety of medications are at our disposal as we battle the phantoms, ranging from painkillers that have been used for thousands of years to drugs developed with 21st century insights and high-tech science.

But a cautionary note must be sounded concerning medications. While they can be useful, medications are not a complete or magical solution. Pain pills should be viewed merely as tools that assist in taking the edge off pain. They can lessen discomfort and help put pain in the background, thus allowing a person to better focus on other matters, but they are not a cure. Those healthcare providers who prescribe medicines know the medication is not a cure, but may not convey that to the person in pain. This leads to a mismatch in expectations and more frustration. An antibiotic can wipe out an infection, but a pain pill does not eliminate pain. Medications may lower pain’s intensity or reduce the frequency of pain episodes, but they don’t necessarily change the underlying source of the pain. And, used incorrectly or in excessive amounts, pain medications have the potential to harm.

Narcotics

Opiates and narcotics have been used since ancient times to treat pain. But, while we use narcotics extensively around the time of surgery, we usually try to avoid them long term because they are the classic example of what we just discussed. Narcotics calm our reaction to the phantoms, but they don’t make the phantoms disappear. Unfortunately, there are some people who may well need a low level of chronic narcotic medicine, but typically only as a last resort when other strategies have not helped.

Narcotics don’t act at the source of the pain. Instead, they work in nerve centers and the brain. The pain is still there, but it’s not as bothersome. An accident victim who is receiving morphine will say the morphine is helping him tolerate the pain. But, if you ask if he still hurts, he’s likely to say, “Yes, but I don’t mind as much.” The broken bones are still transmitting pain messages, but the brain no longer cares much about them. The opiate forms a cloud-like barrier that hampers pain signals being transmitted between the injury site and the brain, and the person becomes more indifferent to pain.

Traditional narcotics have a very fast onset and a high initial peak effect. But that effect wears off quickly and the pain recurs. As tolerance for opiates increases, often more of the narcotic is needed to produce the same effect, and it may be needed more frequently. An



array of safety risks accompanies the use of narcotics, including decreased reaction time, clouded judgment and drowsiness. In large doses, narcotics can inhibit respiration, making breathing difficult or even impossible.

As we've attempted to treat postoperative pain with better control and delivery of narcotics, we've seen a subtle rise in complications that can be life threatening. I know of one instance where a mother, eager to lessen her daughter's suffering, was activating the girl's push-button pain medicine system whenever the daughter stirred or looked uncomfortable. Instead of allowing the girl to use the patient-controlled analgesia device herself and determine her own dose, the mother was giving her more and more medication. She had good intentions, but her actions caused the girl's respiratory rate to actually stop. Fortunately, the daughter was resuscitated successfully.

Newer, longer-acting narcotics linger in a person's system for more extended periods of time. They do not have the rapid, high peak and fast wear-off that characterize traditional opiates. The newer narcotics take effect more slowly and are designed to maintain a steadier state, avoiding the rapid high and drop-off. Such drugs do have dangers, however, and misuse of them is increasingly common.

Recent articles in newspapers and magazines highlight the "Oxy abuse epidemic," cases in which the pain reliever

OxyContin has been crushed and used as a street narcotic by addicts, who have sometimes died from overdose. On the street, these drugs can be manipulated to take away their long-acting nature. This creates a tremendous dilemma for physicians and providers: balancing when these drugs can truly improve a person's life while at the same time minimizing the risk of abuse to society. Some states limit the amount of such drugs that can be included in a single prescription or closely scrutinize with a suspicious eye those physicians involved in prescribing these drugs. Addiction risks, for both psychological and physical dependencies, mean that narcotics typically lie on a path of treatment that we don't want to stay on for long, if we venture onto it at all.

Antidepressant Medication

Some antidepressant medications are used to treat pain. Until recently, the antidepressant Amitriptyline often was the first medicine considered in the medicinal battle against phantom pain. But many patients complained of side effects such as a dry mouth and that the drug altered the taste of food. Drowsiness was another major complaint. And while inducing drowsiness in the evening was beneficial for some to help them sleep, many described a morning hang-over effect that made them groggy the following day. Another antidepressant, Nortriptyline, had fewer side effects, but didn't seem to work as well.

Physicians and patients should be asking themselves whether the person with

limb loss is also experiencing real clinical depression, which might cause phantom pain to be more bothersome or occur more frequently. While antidepressant medications may not be ideal, they do work for some individuals with phantom pain, while also treating depression. Thus, diagnosing and appropriately treating clinical depression can have the added benefit of helping some individuals with their phantom pain.

Antiseizure Medication

Antiseizure drugs have been used for years to combat phantom pain, with Neurontin (gabapentin) emerging most recently as a front line medication. Antiseizure drugs can be effective in calming excited nerves, and many report that they minimize the number of episodes of phantom pain. I had a patient with limb loss who pointed out that his brother-in-law had seizures after sustaining a severe head injury. He then inquired whether his phantom pains were like seizures in the nerves of his amputated leg. It's not a perfect analogy, but, in a way, the comparison is appropriate. Antiseizure drugs can be effective in calming bursts of nerve activity, whether those bursts occur in the brain or a limb.

Traditionally, Dilantin, Tegretol and Phenobarbital were used, but these medications carried higher risks of side effects, such as drowsiness, dizziness, confusion and osteoporosis. Neurontin is a newer antiseizure drug that seems to lower the number of pain episodes and their intensity with fewer side effects.

While not an antiseizure drug, an oral form of lidocaine used to treat heart arrhythmia is also occasionally used for amputee pain. Just as it calms excited nerves in the heart, it can calm excited nerves in a limb. But close attention must be paid when starting such medication to make sure that heart rhythm problems aren't induced.

Anti-Inflammatory Medication

Anti-inflammatory medications actually reduce the inflammatory response at the site of injury, overuse and trauma. Unlike narcotics that act in the brain, these medications actually change the local condition and decrease the stimulus to excite the pain fibers. The major risk of all anti-inflammatory medications is stomach irritation, bleeding or ulceration. For some individuals, they can also affect the kidneys.

While anti-inflammatory medications like aspirin and ibuprofen are not specific in the treatment of phantom pain, we know that overuse and local injury can make phantom pain worse. Anti-inflammatory medications do have a role in treating these local conditions that individuals with limb loss frequently suffer, and since the local irritation can precipitate phantom pain flare-ups, they may have an indirect role in treating the phantoms.

Medical Marijuana

Is there a place for marijuana in fighting the phantoms? It's a very controversial subject. There is anecdotal support for marijuana as a source of pain relief, and voters in some states have approved measures in support of marijuana for medicinal purposes. In some states, physicians may tell patients they support the use of marijuana to treat pain when all other painkillers have proven ineffective, but they cannot actually prescribe marijuana. Instead, doctors document in the medical record that marijuana provides the only effective relief for that individual. If the person has a written statement from a doctor explaining that marijuana provides the only effective relief for their pain, then select

law-enforcement agencies have indicated they may not be inclined to prosecute. It's a thorny issue that varies greatly among the different states - and one that can put both patient and doctor in a precarious legal situation.

Officially, marijuana use remains illegal by federal law. Marijuana is a Schedule I drug, as defined by the Controlled Substance Act of 1970. Congress has rejected attempts to reclassify marijuana as a Schedule II drug, which would create exemptions for its use as a medical necessity, and the Supreme Court of the United States has ruled there is no legal authority for use of marijuana as a medical necessity.

There is little in the way of reliable research that addresses many unresolved questions associated with any proposed legitimate use of marijuana. How does one determine a safe, effective dose? How many doses per day are indicated? What are the risks associated with use of marijuana over long periods

of time? What are the side effects, and do they outweigh the benefits? While our interest in finding and using effective pain-relieving drugs remains high, we must balance our hopes with reliable scientific research that attempts to prove the efficacy and hazards of these drugs.

The U.S. Food and Drug Administration (FDA) has approved Marinol, an oral medicine containing a synthetic form of the active ingredient in marijuana, for two purposes. It may be used legally for treatment of nausea associated with cancer chemotherapy by patients who have failed to respond to conventional treatments. Marinol is also indicated to treat weight loss in cancer or AIDS patients. Its use for pain control has not been documented and is not approved.

Other Supplements

Vitamin and mineral supplements have been increasingly used to treat nerve pain. Deficiencies in vitamins, especially the B vitamins, and in trace minerals

such as calcium, magnesium and zinc have been associated with worsening pain. Good diet and nutrition are important in maintaining overall health. We usually suggest people take a good daily vitamin and mineral supplement.

Each person should discuss thoroughly with his or her doctor the pros and cons of medications and supplements so that an informed, wise choice can be made. Both prescription and nonprescription treatments, such as vitamins and those products labeled as “dietary supplements,” should be discussed to determine any risks.

Some dietary supplements are praised in conversations and Internet chat rooms for treating a wide variety of conditions. For many individuals, they seem to work very well. But there frequently is very little in the way of scientifically sound research to document many of these claims. There may be elements of validity to the reported benefits of some of these products, but science has not yet put together a body of evidence to support many of the claims.

Many medications and dietary treatments have anecdotal support, rather than proven scientific benefit. Anecdotal support - also known as “word of mouth” - happens, for example, when someone in a support group says, “This worked for me.” Others then are willing, sometimes eager, to try it, too. But the most valuable and reliable scientific information about a drug or supplement comes through clinical trials. In a clinical trial, a preparation is tested against another treatment or against a placebo to collect scientific data. In quality, insightful trials, some supplements that have anecdotal support don’t look so promising or even effective when they are scientifically measured and studied. Unfortunately, dietary supplements often are not exposed to such formal study. And dietary supplements need not be subject to scrutiny by the FDA before they are allowed onto store shelves.



“The best weapon against phantom pain may come from within.”

Attitude Counts

The best weapon against phantom pain may come from within. Dee Malchow is a registered nurse, an amputee and a counselor who has provided me with many valuable insights learned from dealing with her own amputation-related pain. She says, “Pain is inevitable, but misery is optional.”

Dee calls limb loss “a tremendous assault to the body” and notes that it’s not unusual to experience some ongoing sensitivity in the area of amputation for life. “So the goal is not to let that sensitivity call the shots the rest of your life,” Dee says. The goal is learning techniques that help you manage pain issues. “Avoid letting the pain overtake your entire life.”

Some pain-treatment centers require that their clients keep a journal to catalogue, measure and follow their pain. A diary may be useful for periods of time

when tracking the effect of a new intervention, but focusing on the condition to the point of obsession can make it feel worse. Dee advises that distraction can be a useful weapon in fighting the phantoms. “Especially with phantom pain, the more you focus on it, the worse it is,” she says. “The more attention you put on it, the more painful it is.” While keeping a log or a diary may have a role in evaluating a new treatment, it’s difficult to write about your pain and work on distraction techniques at the same time. For some folks, keeping a log may not be a good idea.

All of us have energy limitations. Over-exertion can induce mechanical pain and influence phantom pain as well. When you’re out shopping all day, you know that you are not going to come home and mow your lawn, so listen to your body. For some, inactivity seems to bring on phantom pain; others tell me activity helps ease their phantom pain. Discover what works for you.

One of the best prescriptions we can give ourselves is to take charge in fighting life’s challenges. Attitude counts. Amputation is an extremely significant loss, but we have the power within ourselves to decide whether it is going to make us a victim. “It’s a nuisance you learn to put up with in life,” says Dee, who lost her foot while a teenager. “Move ahead. Take charge of your life.”

In a perfect world, no one would suffer. But there is not, and probably never will be, a pill to take away every kind of pain. For people with lifelong conditions, we must continue to seek the most effective ways to treat and manage pain as a part of one’s life, rather than allowing pain to become the focus of life. ■

*Next Issue: The Phantom Menace III
(Fighting the Phantoms: Use of Modalities)*