

PART III

NOTES From the Medical Director



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THE PHANTOM MENACE II

PHYSICAL MODALITIES



“For the patients, long after the amputation is made, say they still feel pain in the amputated part. Of this, they complain strongly, a thing worthy of wonder and almost incredible to people who have not experienced this.”

- Ambroise Pare, 1551

We have long known about phantom pain. The above comment by French surgeon Ambroise Pare was written in 1551. Phantom pain is real, but it can seem as mysterious to us today as it was to Dr. Pare more than 450 years ago.

In Part I and Part II, we attempted to define the phantoms, distinguish the characteristics that make phantom sensation different from phantom pain, and focus on medicinal therapies and the importance of a positive attitude in our fight against “The Phantom Menace.” We now turn our attention to the array of physical modalities, both active and passive, that can be useful in the ongoing battle with phantom pain.

Many people with limb loss have an underlying hope that healthcare practitioners have the solution to phantom pain. We hope there is a technique, a pill - anything - that will remove the discomfort. It’s a pain to have pain. But

it’s not that simple. Pain is a complex, multifaceted entity. What may be agonizing to one person may not be terribly bothersome to someone else. Methods to deal with pain are as varied as the people who have it. What works well for one person might not work at all for another.

Public awareness of pain issues has emerged as society increasingly asks for ways to lessen suffering. Some hospitals even post signs that say “You have a right not to be in pain” as part of a “Patients’ Bill of Rights.” Eliminating pain altogether is an ambitious and laudable goal. But reality intervenes. It is not possible, currently, to eliminate all types of pain. Pain is part of injury. Pain is part of surgery and recovery. Pain is often a part of illness. The goal to eliminate pain entirely for everyone may never be achieved. A more realistic, and accomplishable, objective can be to practice ways of better coping with pain and reducing its impact on our lives.

Therefore, it is important to keep an open mind when discussing the wide range of pain treatments. In our search for answers, we should consider both traditional and nontraditional methods. Our aim is to help people attain those worthwhile elements they feel are important for a higher quality of life. We endeavor to use drugs in treating pain for as short a time as possible. There’s certainly a time and place for drug therapies, but our ultimate goal is to enjoy a meaningful life without the side-effects or addiction problems that can accompany medicinal therapies.

Nonmedicinal therapies generally are not invasive, which is good. But solid, reliable scientific evidence to support claims for some modalities is rare or non-existent. It’s only somewhat recently that the scientific community has begun to put together solid research data on the effectiveness of different medicines. In general, many of the nonmedicinal physical treatments are even more difficult to study scientifically, and there’s much less scientific data available. It’s good to be open-minded and curious, but a little skepticism is healthy, too.

Distracted? Good!

Pain thrives on attention. We conducted a pain study in which participants were asked to rate their pain each week on a scale from one to 10. One person said, “I can’t stand being in this study. I didn’t realize how much pain I was in until I had to rate it. Now that I’m paying attention to it all the time, I hurt. I don’t want to think about it anymore.” This person wanted those distractions that help us live a normal life.

Some pain-treatment centers suggest, or even require, that clients keep a journal to catalogue, measure and track their pain episodes. Such a diary may be useful at times, such as when following the effects of a new drug or intervention, but focusing on the condition to the point of obsession can make it feel worse. Dee Malchow is a registered

nurse and amputee counselor who lost a foot when she was 19. As she noted in our last article, distraction can be a useful weapon in fighting the phantoms. “The more you focus on phantom pain,” she says, “the worse it can be.”

Pain Shouts - You Should Speak Up, Too

You may not want to keep a journal, but that doesn't mean you should keep silent about phantom pain. Some people have misgivings about discussing their phantom pain because they're afraid others may not believe them or will think they're mentally unstable. Dr. Richard Sherman notes that at one time, no more than 5 percent of people who had lost a limb to amputation were believed to experience phantom pain. But once amputees discarded their fears of being thought of as “crazy,” and acknowledged out loud that they'd experienced it, healthcare professionals realized the actual number of people who'd had phantom pain was closer to 80 percent, according to Sherman. Of those, some 5 to 10 percent experienced such intense phantom pain that it disrupted their lives in a major way.

Don't be afraid to acknowledge phantom pain and the things in life that trigger it. Phantom pain can occur with various bodily functions, such as urination, bowel movements or sex. Phantom pain episodes at such times can be frightening, and many people are relieved to find that these associations happen to others, too. They'd thought it happened only to them.

You've Got Your Nerve(s)

Nerves transmit pain signals to the brain. It's important to avoid direct pressure on top of the nerves. Nerves like to be protected. Maintain muscle tone in the amputated limb with exercises. A well-fitting prosthesis and adequate padding between the residual limb and the prosthetic device is very helpful. Many of the innovations in liners and prosthetic interfaces are aimed at protecting the skin and nerves.

Nerves, muscle and bone are designed to be active and functional, and nerves respond to functional activity. Stretching the limb, gentle massage, a shower, a walk while wearing a prosthesis and isometric exercises while sitting in a chair or a car might help us cope with discomfort. Sometimes, removing the prosthesis for a short while, slightly adjusting it, or using an Ace wrap can help. Some people wear shrinker socks or a roll-on liner at night when they say their problems with pain are worst.

While exercise is beneficial for many reasons, overdoing it is not. Everybody has wear-and-tear problems. And when you have one arm, chances are greater that you'll have problems related to your rotator cuff, a “tennis elbow” kind of epicondylitis, or carpal tunnel than if you had two limbs to share the load. Pain problems from overuse occur in a higher percentage of people with limb loss than in the population as a whole.

My Aching Back

Back pain is part of the human condition. Eighty percent of the population has back pain severe enough that at some point they miss work. People with

limb loss, upper or lower, have a higher incidence of back and neck pain. Gait abnormalities and asymmetry with lower limb loss, as well as postural changes that occur with upper-limb loss, can have a real impact on your back. We did a survey and what really jumped out at us was the number of people who said, “Back pain is what's keeping me from doing what I want to do.”

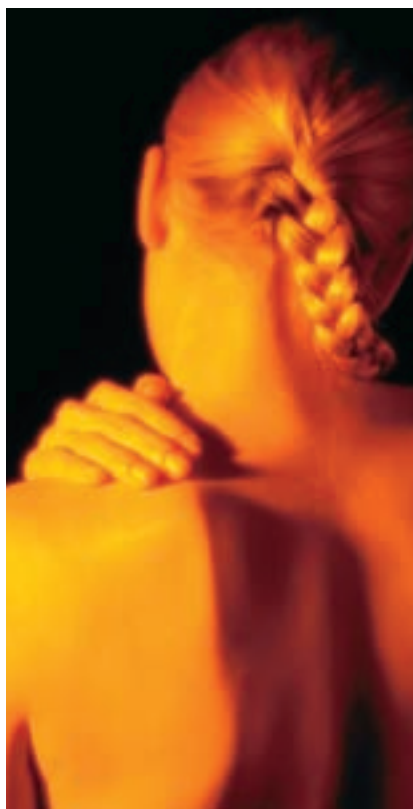
In addition to gait training, people with limb loss find it beneficial to learn prevention strategies, stretching techniques and exercises to care for their backs. Learn to sit and stand properly. Learn to lift correctly. Learn stretching techniques. It benefits all people to educate themselves about body mechanics. Your back will thank you.

Wired

Transcutaneous Electrical Nerve Stimulation (TENS) units consist of a battery pack with electrodes. These electrodes are attached to the skin and transmit a mild electrical current. TENS therapy overrides pain nerve fibers with constant low-level electrical stimulation through the skin (transcutaneously). The intensity can be controlled so the person receives constant stimulation, pulsations or intermittent bursts. TENS therapy offers nerves stimulus other than pain. TENS can be very helpful for some people, especially in the short term.

Many people discontinue TENS therapy after a few months. It may be that the treatment becomes less effective over time, or perhaps the users have worked through the worst of their pain at that point and the need for TENS treatments has lessened. TENS therapy typically is used early in the postoperative period, and symptoms may diminish with time and therapy. Or, since we're attempting to override nerve impulses and “trick” them into focusing on a stimulus other than pain, the nerves may not remain “fooled” for very long.

Biofeedback proponents say anxiety and tension may aggravate phantom pain,



causing muscles to clench. In biofeedback therapy, electrodes attached to the residual limb signal muscular tension. The person then relaxes the muscle until the feedback stops. The person learns to relieve tension by relaxing the muscles. Eventually, users of biofeedback say they learn to recognize the signals of tension without the use of technology and make themselves relax.

Hands On

Massage is one of the oldest and most popular forms of hands-on therapy. Touching and rubbing a painful area can relax the muscles, stimulate the nerves, improve blood flow and provide relief. Shiatsu is a Japanese practice in which pressure ranging from moderate to deep is applied with fingers, thumbs, palms, knuckles - even elbows or feet - to key parts of the body. Shiatsu and other forms of massage can be performed repeatedly.

Two traditional Chinese techniques, acupressure and acupuncture, have

gained a wider audience in the West. Both acupressure and acupuncture are based on the concept that energy travels through the body along pathways called meridians. According to this theory, blocks in that energy flow can result in discomfort or even disease. To promote energy flow, the acupressure specialist presses “acupoints” on the body. Acupuncture follows a similar philosophy, but in acupuncture slender needles are inserted into certain parts of the body to interact with energy flow.

Chiropractic therapy focuses on bodily structures. Chiropractors traditionally concentrate on the spine, but they also can manipulate other areas. Physical adjustments of bodily structures are aimed at relieving strain on joints and reducing pain.

Some people are combining the concepts of energy emanating from the body with physical manipulation. Practitioners believe that both the physical body and its energy field can be manipulated

with special hands-on techniques to lessen discomfort.

Hands Off

Others concentrate on massaging the body’s energy field alone. This technique has several names, such as “therapeutic touch.” Practitioners say massaging and manipulating an energy field that surrounds the body corrects imbalances in that energy and makes the recipient feel better. This is harder to measure, scientifically, but some who’ve been treated with therapeutic touch say their anxiety lessened and that it helped them to better cope with pain.

The Eyes Have It?

Eye Movement Desensitization and Reprocessing (EMDR) is a technique in which patients follow a light or moving object with their eyes as they think about a traumatic incident in their lives. EMDR practitioners say rapid eye movement stimulates the brain to reprocess painful memories and activate emotional mechanisms to help cope with traumatic episodes and their aftermath. While EMDR has anecdotal evidence to support it, clinical evaluations and scientific trials have produced mixed results as to its effectiveness.

Mirror, Mirror

Studies by Dr. Vilayanur S. Ramachandran involve mirrors in treating phantom pain. He describes a man whose left arm was amputated at the shoulder following a motorcycle collision. Ten years after this man lost the arm, he continued to feel phantom pains in his missing arm, and the phantom limb felt fixed in an uncomfortable position. Dr. Ramachandran had the man place his right hand in a “mirror box” that used reflective glass to create the image that the man’s right hand was where his left one would have been. The man “placed” his phantom limb inside the box, then “moved” both limbs. The man excitedly said he immediately could move his missing arm when he looked at the reflection of the other arm. But when he closed his eyes, he no longer could move the phantom

limb. When he opened his eyes again, he once again moved the phantom limb.

Dr. Ramachandran suggests that the neural circuits that normally would have moved the phantom limb were inhibited or blocked. When the man had visual feedback, his phantom limb no longer felt awkward and he could move it freely. Using muscle-release actions in both arms, people with a fixed phantom sensation are able to relax these muscle-cramping positions.

Magnets: They Attract and Repel

The use of magnets to treat pain sparks plenty of discussion among advocates and naysayers. You might say that people find magnet therapy either “attractive” or “repelling.” Advocates claim placing magnets over the affected area relieves pain. They say magnets can improve blood flow in residual limbs, which could have a positive effect on phantom pain. Magnets and certain metals, by themselves or when woven into the fabric of clothing, are said to help protect against problems caused by electromagnetic fields. Some individuals say that magnets improve pH imbalances. But skeptics counter that there is little in the way of quantifiable scientific evidence to support claims of the healing properties of magnets. They argue that any perceived benefits could be merely a “placebo effect” and that users say magnets “work” because they are persuaded by the belief that the magnets are supposed to work.

Could magnets have an indirect effect on phantom pain? A study at Emory University, which was published in the journal *Psychiatric Annals*, reported success in treating some cases of severe depression when powerful electromagnets were applied to a person’s head. Alleviating depression is beneficial. When we feel better emotionally, we feel better physically.

Running Hot or Cold

Applying heat or cold to the residual limb is touted to provide pain relief. Some advocate heat; others like cold. For some, a combination that alternates the application of heat and cold is best. Heat can help stimulate blood flow to the area while relaxing the muscles. Cold refreshes the area. What’s right for you? Give each a try and see whether you derive any benefits. As with all physical modalities, the technique that works well for one person sometimes has little or no effect at all on another.

Rub It In

Topical agents can help, or hurt, but they are best tolerated when exposed to open air. A cream or ointment applied to the skin of the affected area may bring varying degrees of relief; however, if it is applied to a part of the body that comes into contact with a prosthesis, or if it is used in an enclosed area that gets little air circulation, it can sometimes be bother-

some. For example, some people find topical relief with a pepper extract ointment. But that same ointment can cause discomfort or even burning if it is used on an area that’s covered by a prosthesis, which can magnify the effect.

Typically, a person should try using a topical ointment on an unaffected part of the body for several days to see whether there’s any unwanted reaction. If not, then you can gradually apply it to the area of pain to see how well you tolerate it. There may be a desire to use a product that masks or



deodorizes an area of the skin that contacts or is surrounded by a prosthesis, but this may cause more problems than it solves. Soaps, ointments, creams and perfumes that do not affect the skin when exposed to plenty of fresh air may cause skin reactions when they're under the pressure and constant forces of a prosthetic device. In addition, certain soaps and perfumes may cause contact dermatitis.

Food for Thought

Good nutrition rejuvenates body, mind and spirit. A well-balanced diet provides us with the vitamins and minerals we need, and good nutrition makes us feel better. In recent years, dietary and herbal supplements have drawn increasing attention. There is often much word-of-mouth support for many of these supplements. Support group leaders tell me that there is excited talk among their members about potassium, calcium and magnesium for reducing phantom pain. And antioxidants and bioflavonoids found in certain foods and vitamins are much discussed because of their purported benefits in removing toxins from our systems.

But remember: While many of these supplements may be "natural" that doesn't automatically mean they are free from any side-effects. Unwanted interactions can occur with prescribed drugs. While some people say that food or supplements help relieve their phantom pain, others say certain foods can set off phantom pain or make their pain episodes worse.

Too frequently, there is little in the way of thorough scientific research to back up some of the claims involving food supplements and herbal treatments. The U.S. Food and Drug Administration does not regulate a great many of these



items, so some claims may not be subject to either scientific or government scrutiny. Discussions with your pharmacist or physician can shed light on benefits and possible drawbacks.

We Need Each Other

It's nurturing to be with those people whom we care about and who care about us. Humans are social animals. While we might prefer being alone at times, usually at some point we all desire the company of others. Sharing part of a day, enjoying an outing, or a phone call to a good friend can brighten our outlook. Sometimes, being with others provides us with a needed diversion from a problem. We're living life, enjoying it with somebody. Smile, laugh, tell a joke - humor is terrific therapy and a good coping mechanism.

In this series of three articles, we have tried to highlight the huge array of therapies to treat phantom pain. Many approaches have been used and continue to be tried because a single solution for everybody just does not exist. Dr. Pare first described phantom pain more than 450 years ago, but it wasn't until shortly after the Civil War that Dr. Silas Weir Mitchell described a "ghost" sensation in the missing limbs of soldiers, giving us what's considered the initial "modern" era report of phantom pain. Clearly, the answers to the mysteries of phantom pain don't come easily, or quickly. There is much about phantom pain that we have yet to learn. But as we continue to ask questions, probe and understand, we gradually take more and more of the menacing elements out of "The Phantom Menace." ■