

## PART I

NOTES From the Medical Director



# THE PHANTOM MENACE

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**P**hantom sensation. Phantom pain. Sound ethereal, don't they? Vaporous.

Ghostlike. Synonyms for the word "phantom" include "apparition," "illusion," "immaterial," "nonexistent" and "thing imagined." But we can throw out those synonyms. When talking about phantom sensation and phantom pain, these phantoms are REAL.

These phenomena do, in fact, exist, and they can be complex, manifesting themselves in a variety of forms, feelings and sensations. Some phantoms bring pain; others do not. That is why health-care providers have started to use the words "phantom pain" and "phantom sensation" differently. Both phantoms are real, but they are very different from each other.

Explaining the kind of sensation or pain we're feeling can be tricky. What are the right words to convey to another person just exactly what sensations we're experiencing? The terminology can be confusing. Many people have told me that they have phantom pain constantly. But when we closely examined what they were saying, we found that they were actually describing phantom sensation. Fortunately, these sensations didn't bother them too much. Others, however, were describing something that seemed very different: more episodic, more burst-like, more severe and more intense. They were describing what is referred to as phantom pain.

It is helpful to use descriptive terms to characterize and illustrate the feeling. I like to ask a person, "Is it constant or episodic? Does it occur frequently or rarely? How long does it last? Do you experience it at certain times of day more than others? Would you describe it as intense,

or is it kind of 'in the background?' Is it a sharp pain, or a dull sensation? Does it itch? Is it a burning sensation? Is it bothersome, or not?" Descriptions of the feelings are useful tools in trying to determine exactly what the person is experiencing.

Almost every person I know who has lost a limb or part of a limb experiences phantom sensation – the sense that all or part of the missing limb is still attached. One person may describe the sensation as tingly. Another says it feels as if he's wearing a sock on his foot. Some describe it as a feeling of exaggerated position and say, for example, that their missing hand feels like a tightly clenched fist or that their wrist feels as if it is extremely bent back. Phantom sensation is the perception that some or the entire missing limb is still intact. The sensation frequently feels as if it's in the background; its intensity varies only to a minor degree and people's awareness of it increases only when they are paying attention to it. When their thoughts are elsewhere, the sensation is less noticeable.

While phantom sensation usually is not bothersome or painful, it can be, and when it is painful, our current descriptive words get confusing and fail us. Phantom pain, typically, is more episodic. It usually comes in bursts, striking quickly. Some who have experienced it say they were jolted to a halt by it – stopped in an instant. The duration of these episodes can vary, ranging from a few seconds to minutes and, unfortunately, sometimes much longer.

A patient trying to explain the sensation told me: "My brother-in-law had a head injury, and now he has seizures that come on. They try to treat them

with medicine to minimize their number and intensity. I had an amputation. Is what you're talking about the seizures that happen in my leg?" It's not a perfect analogy, but it's not bad. People who have had a severe head injury often have seizures afterward; people who have had amputations often have bursts of nerve activity that we call phantom pain.

When burst-like episodic pain occurs, a multitude of nerves start firing, activating the receptors and neurons in the cortex of the brain. Special medical scans can illuminate the parts of the brain that are activated and firing during these episodes. While we can't actually see the pain, these scans do reveal to us which parts of the brain are turned on when phantom pain hits.

We know that phantom pain is real, but there's much about it we have yet to learn. People tend to think "Uh-oh, what's wrong with me?" when they're told it might be in their head. People with limb loss may feel especially vulnerable – how can there be pain in a body part that is no longer there? But that doesn't mean they're imagining something that doesn't exist. What it may mean is that phantom pain is the result of literal physical activity in the brain that registers as pain.

Research data about phantom pain can be revealing, but making an accurate determination of what these statistics actually show us can be more elusive. One study may say that 85 percent of people with limb loss "have" phantom pain. Another study might indicate that just 10 percent of people "suffer"

from phantom pain. Are these studies in conflict, or do they indicate that while most people experience some episodes of phantom pain, a smaller percentage find it bothersome enough that they suffer. Statistics can be short on specifics. Also, the way a question is worded can result in different answers. There are differences between “Do you have phantom pain?” “Are you bothered by phantom pain?” and “Do you suffer from phantom pain?”

I think that 100 percent of amputees experience some kind of phantom sensation or pain. And while 85 to 90 percent of all amputees might have some episodes of pain, the true percentage of people who have a major debilitating problem with phantom pain is, fortunately, much less, probably between 5 and 10 percent.

It’s important for healthcare professionals to track the frequency of phantom pain episodes. How often do these episodes occur – 10 times a week, or once a month? Using the seizure analogy again, if someone is having 10 seizures a day, that’s a big problem. But if the number of seizures can be reduced to one a month, or one a week, that’s a big improvement. In the same way, if a person with phantom pain is having five episodes a day, and we can reduce them to two a week, then that can be a successful way to determine whether the treatment is working. In addition to the frequency of the episodes, we also look at their duration and intensity.

We know from historical data that mechanical causes of pain, such as neuromas, tethered nerves, pressure points and bone spikes, are more likely to respond to surgical treatment. Phantom pain, unfortunately, does not typically respond to surgery. Like detectives looking for clues, when we search for the causes of pain, we look for both obvious and subtle evidence. We first hunt for those causes that are more mechanical in nature and, thus, more directly treatable. We also look for anything that’s unusual, such as tissues or structures that look abnormal and may be causing pain. But the painful area may not present any kind of obvious, outward sign. The healthcare provider’s task is to

examine an array of symptoms, consider the person’s descriptions of the sensations or pain, and then put that information together the way a detective would assemble clues to form a mental picture.

Sometimes, like determined cops, we get “our man” right away. The cause of the discomfort is pinpointed, and we can launch a course of treatment. At other times, the hunt is elusive, and the investigation into the cause and a possible remedy stretches out over time. It’s not that “bad cops” are working the case; rather, the solution remains just out of reach, even for those who are pursuing it exhaustively.

*“The universe is like a safe for which there is a combination, but the combination (may be) locked up in the safe.”*

– Peter de Vries, author

Is the solution to phantom pain like this elusive combination? Perhaps. No doubt, treating phantom pain is certainly not easy. We know when we have it, but we’ve had little success finding ways to stop it.

Over the years, we’ve used surgery,

injections, oral medications, pumps and stimulators, passive therapies, such as relaxation and baths, and more active modalities, such as acupuncture, acupressure, massage and exercise, to treat pain. We should be open to considering all forms of treatment, even those we don’t immediately understand. Just because something isn’t wholly understood doesn’t necessarily mean there isn’t good science behind it. It may be science that has not yet been quantified and qualified.

Pain is not a single entity. It has many qualities. There is no such thing as “the answer” to conquering pain. The answer is different for each of us. Until the myriad phenomena of pain are better understood, treatments are difficult and often indirect. These phantoms are real, and as our scientific understanding improves, we strive to take more of the haunting mysteries out of them. ■

*Next: The Phantom Menace II (Fighting the Phantoms)*