CANCER*CATE* 

## Understanding Peripheral Neuropathy

Presented by

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Learn about:

- Causes of peripheral neuropathy
- Treatment options
- Working with your health care team
- Tips for coping with neuropathy



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INTRODUCTION	page 2	
FREQUENTLY ASKED QUESTIONS	page 13	
GLOSSARY (definitions of blue boldfaced words in the text)	page 15	
RESOURCES	page 16	

This patient booklet was made possible by a charitable contribution from Bristol-Myers Squibb and an educational grant from sanofi-aventis U.S. LLC. Because there are many causes of peripheral neuropathy, it's important to get the right diagnosis.

People living with cancer may experience nerve symptoms, which they often describe as pain, tingling, burning, or numbness. Some people with cancer also have problems with coordination. All of these symptoms may be caused by **peripheral neuropathy**. In this condition, nerves outside the brain and spinal cord have been damaged, often by the cancer treatments themselves. Sometimes the symptoms are temporary and gradually decrease after the cancer treatments are completed. At other times, the



symptoms persist, requiring ongoing medical attention and care. Sometimes the neuropathy affects only one nerve. At other times, it occurs in several nerves.

Although peripheral neuropathy may be a side effect of cancer

treatment, it may also be caused by other conditions not associated with cancer, such as diabetes. That is why it is so important to get a proper diagnosis—that is, find the right cause—for this condition.

To do so, doctors consider differential diagnoses—a list of

all the possible causes for the symptoms. They then weigh the likelihood of one versus another as being the reason for the symptoms. For example, coughing and sniffling could be caused by hay fever, the overuse of a nasal decongestant spray, or the common cold. Peripheral neuropathy could be caused by the cancer itself, cancer treatments, or other

### Symptoms of Peripheral Neuropathy

**S**ymptoms depend on which nerve is involved, the cause of the condition, and the length of time the neuropathy has been present. Major symptoms may include any of the following:

- weakness
- pain
- muscle loss
- loss of feeling in a particular area
- loss of or reduced reflex responses
- burning sensation along the route of a nerve in the body
- tingling sensation in the hands, feet, or other parts of the body
- sharp, shooting, electric shock-like pain
- allodynia—pain from something that wouldn't normally cause pain, such as stroking the hand
- hyperalgesia—exaggerated pain response to something that would normally cause only mild pain, such as a pinch to the skin

Less commonly, neuropathy can lead to:

- urinary incontinence
- constipation
- impotence—the inability to have or maintain an erection
- dizziness when standing
- increased risk of falling from poor balance

conditions, as we discuss below. Understanding the cause helps doctors offer the right treatment.

# What Causes Peripheral Neuropathy?

In people with cancer, peripheral neuropathy is usually caused by damage to nerves from surgery, radiation treatment, or chemotherapy. It can also be caused by a tumor pressing on or penetrating a nerve, or an infection that affects the nerves, such as **shingles**. Excess alcohol use or **chronic** health problems such as diabetes can cause or contribute to neuropathy as well.

### SURGERY

Surgical treatments of cancer may damage nerves that lead to neuropathy. Some people experience sensations of burning, shooting pains, electric tingling, or numbness in the skin around the surgical site.

### **RADIATION TREATMENT**

Neuropathy resulting from radiation treatment was much more common in the 1960s, when such treatments were not as sophisticated as they are today. At that time, arm weakness and pain sometimes developed several years after completing radiation treatments. Fortunately, techniques for giving radiation have been finely tuned since that time. Neuropathy due to radiation is much less common today but may still occur.

### **CHEMOTHERAPY**

Chemotherapy can cause neuropathy, most commonly polyneuropathy, which involves several nerves in the body. This condition usually affects both sides of the body equally. Symptoms often begin in the feet and progress to the hands, what doctors call "stocking/glove distribution." Several types of chemotherapies may cause peripheral neuropathy, including docetaxel (Taxotere), oxaliplatin (Eloxatin), vincristine (Oncovin and others), vinblastine (Velban and others), paclitaxel (Taxol and others), cisplatin (Platinol and others), and carboplatin (Paraplatin and others). Neuropathy brought on by chemotherapy can be short-lived or become chronic, depending on such factors as a person's age, a person's **genetic predisposition** to neuropathy, the amount of each dose of chemotherapy, the total dose of chemotherapy received over time, and the combination of different drugs received. People who already have neuropathy due to another condition run an especially high risk of their neuropathy becoming more severe when they receive chemotherapy that can damage nerves.

# Treatments for the Pain of Peripheral Neuropathy

Typically, doctors treating neuropathy aim to reduce pain. Commonly used treatments include:

 Antidepressant medications, such as amitriptyline (Elavil and others), nortriptyline (Aventyl, Pamelor, and

others), and desipramine (Norpramin and others), may help relieve the pain of peripheral neuropathy. Doses prescribed are often smaller than the doses that doctors typically use to treat depression.

Anticonvulsants, alone or in combination with

antidepressant medications, can be helpful in treating **neuropathic pain**. Examples include gabapentin (Neurontin and others) and pregabalin (Lyrica).

- Steroid medications are sometimes used in the short run to relieve severe neuropathic pain until a better longterm treatment plan is in place.
- Local anesthetics in the form of patches or creams are applied directly to the painful site and can be especially helpful in managing neuropathic pain. Example of such creams are capsaicin (extracted from chili peppers) and EMLA cream (a combination of local anesthetics). Lidocaine 5%, another type of local anesthetic, is useful in a patch applied to the site of the pain.
- Opioids, such as morphine, oxycodone (OxyContin and others), fentanyl (Duragesic and others), and methadone, are often used in combination with other medications to manage severe neuropathic pain. Opioids are available in long-acting and short-acting pills, patches, and suppositories.

### Non-drug treatments,

including physical, occupational, and relaxation therapy, can be very effective for neuropathic pain. In some cases, treatment involves acupuncture or biofeedback, a technique in which a patient watches measures of his or her own bodily



functions (such as heartbeat, blood pressure, and muscle tension) and learns how to use strategies such as meditation and deep breathing to help control them.

It is very helpful to work with a pain specialist who can recommend a good treatment plan. This is especially important if your symptoms have not responded to your current treatment. A second opinion is always valuable because it either confirms your doctor's advice or offers more information.

### Managing Peripheral Neuropathy

Symptoms of painful peripheral neuropathy may decrease over time. But it sometimes takes one or two years for the symptoms to go away completely. And some people experience longer-term symptoms. There are a number of things you can do to manage the symptoms of peripheral neuropathy and cope with this condition:

- Don't drink alcohol. Even a glass or two of wine or beer can damage nerves, particularly if the nerves have been exposed to chemotherapy.
- Control your blood sugar levels if you have diabetes. High levels can damage nerves, particularly if they have been exposed to chemotherapy.
- Stay ahead of your pain. Take pain medication early in the day, before symptoms become severe. The drugs often work much better this way.

Pay attention to your shoes. Neuropathy often causes foot symptoms. If that's the case, try shoes with "rocker bottoms" smooth soles that have rockers (much like the bottom of a rocking



horse) that allow the foot to roll while walking, taking off some of the pressure. Or, try wearing sneakers and/or using orthotics (customized foot supports) in your shoes. Your **physiatrist**, **physical therapist**, or **occupational therapist** should be able to advise you on where to buy orthotics. Sit down, when possible, if neuropathy in your feet is severe. Set up areas in your home where you can sit to do activities you normally do standing up, such as shaving, putting on makeup, drying your hair, or chopping vegetables, for example. This can make a tremendous difference in how your feet feel.

### **Describing Pain Vividly**

If you are receiving cancer treatment and you start developing pain from peripheral neuropathy, don't self-prescribe over-thecounter medications. Instead, let your health care team know about the symptoms so that an accurate diagnosis of the cause of your pain can be made. The more detailed and precise the information you can give your doctor or nurse, the more it will help him or her treat your pain effectively.

- How intense is your pain? The simplest scale is from 0 to 10, with 0 equaling no pain and 10 equaling the worst pain possible. (Make sure your doctor understands that this is the scale you are using.) Usually, mild pain is considered 4 or less; moderate pain, 5 or 6; and severe pain, 7 or more. By assigning a number to your pain, you are putting it into concrete, measurable terms that health care providers understand. If you have trouble giving a number to your pain, you can use words to describe it, such as mild, moderate, severe, or excruciating. To help young children, people with language difficulties, or those who speak other languages describe the amount of pain they're having, a doctor or nurse may use a series of expressive cartoon faces showing differing degrees of discomfort (see box at right). Sometimes, a thermometer-type scale is used.
- Does the intensity of the pain change during the day or night or with activity? When is it at its worst? When does it seem to ease up?

- Pay extra attention to your feet. At least once a week, use a hand-held mirror to check your feet for sores or open wounds.
- Get a wider grip. If your hands feel clumsy or weak, consider buying household tools such as kitchen knives and hammers with a wide grip. This frees the hand from



Different types of scales used to measure pain intensity

- What does the pain feel like? Is it dull, sharp, stabbing, tingling, burning, throbbing, aching? Is the pain constant or does it come and go?
- How much relief are you getting from any pain medications or other methods you use to manage the symptoms?
- How is the pain affecting your daily activities? Does it affect your mood, your ability to sleep, or your quality of life?

gripping too tightly, which can lead to discomfort. You can also get a non-slip grip for the steering wheel in your car.

Consider using voice-activated computer software if it's difficult for you to type. There are a number of programs and different kinds of equipment that allow you to use a computer without typing, giving the hands a rest. Newer computers have voice-activated software already built into them. All you may need to add to your computer is an inexpensive microphone.

### Working With Your Support Team

### COPING WITH THE SYMPTOMS OF NEUROPATHY

If you are experiencing symptoms of peripheral neuropathy, you may be faced with new questions and choices surrounding your treatment and care. You may feel overwhelmed by these challenges and unsure about where to turn. But help is available.

Pain specialists (including doctors who specialize in anesthesiology or physical medicine and rehabilitation, and nurse practitioners) can provide education about your treatment options and help you manage symptoms of neuropathy that are particularly difficult to treat. Physical therapists and occupational therapists can offer expert advice on the use of special devices, exercises, and other strategies that make it easier to perform day-to-day functions while living with peripheral neuropathy.



### HELP WITH THE EMOTIONAL AND PRACTICAL CHALLENGES OF CANCER

In addition to the support from your health care team, family members, and friends, you can also turn to the following resources for help coping with the emotional and practical challenges of cancer:

**Oncology social workers** are specially trained to help you navigate the sometimes complicated health care system. They also help you and your family sort through the complex emotions and issues that arise. For example, with

peripheral neuropathy, you may be having difficulty with daily activities such as working and caring for your family. It's perfectly normal to feel sad, angry, afraid, or frustrated about how this side effect is affecting your quality of life. Oncology social workers can provide emotional support and guide you to resources. They



also help you communicate with your health care team, thus opening doors to effective pain management. Cancer*Care*<sup>®</sup> provides free individual counseling from professional oncology social workers on staff.

**Support groups** Many support groups are available for people with cancer. Support groups can reduce the feeling that you are going through cancer alone. These groups provide reassurance, suggestions, insight—a safe haven where you can share similar concerns, such as challenges

coping with neuropathy, with your peers in a supportive environment. At CancerCare<sup>®</sup>, people with cancer and their families can take part in support groups in person, online, or on the telephone.

**Financial help** is offered by a number of organizations, including Cancer*Care*, to help cover the cost of medications, transportation to treatment, child care, or help needed around the home. Cancer*Care* can also refer you to other resources in your community that can provide assistance.

To learn more about how CancerCare can help, call us at 1-800-813-HOPE (4673) or visit us online at *www.cancercare.org.* 

## Frequently Asked Questions

## Q Is there anything I can do, such as take a vitamin supplement, to prevent neuropathy?

A Unfortunately, it's often difficult to prevent neuropathy caused by cancer or treatments for cancer. Eating a healthful diet is always important. If you do take any supplements, be sure to tell your doctor, as some over-the-counter products may interact with chemotherapy. In addition, while you're receiving cancer treatment, it's important to avoid alcohol, which can increase the severity of neuropathy caused by chemotherapy. Most importantly, before starting chemotherapy and during your treatment, tell your doctor or nurse if you experience numbness and tingling in your hands and/or feet so that he or she can adjust your medication.

### I finished treatment two years ago, and I still have bothersome neuropathy in my feet. I've been getting acupuncture for a year now, but it doesn't seem to be helping. Should I keep getting acupuncture? Will the symptoms ever get better, or should I just learn to live with neuropathy?

A Acupuncture may help relieve the pain, though the research to confirm its effectiveness is not very strong at this point. It is reasonable to try between six and 12 sessions. If you don't get significant relief at that point, chances are that acupuncture is not going to provide relief. If you've been getting acupuncture for a year with no improvement, it's probably not a good use of your time and resources. You may want to try something else, or get a second opinion with a pain specialist or a **physiatrist**.

### Q My husband resists taking his pain medication until the pain becomes excruciating. I keep trying to tell him that he should take his medication regularly to get a jump on the pain before it becomes unbearable, but I can't seem to get through to him. What can I do?

A Sit down with him and try to find out why he doesn't want to take his pain relievers. People often have false beliefs about pain medications: "If I take my medication now, it won't work later." "If I take opioid drugs, I'll become an addict." "I can't cope with the side effects." Once you identify the issue, you and his doctor or nurse can address it with him. For example, he may need reassurance that even if a particular drug stops working, there are a number of alternative painkilling drugs and different ways of delivering them. His doctor can tailor these drugs and methods to his needs, if his pain persists.

If your husband worries about becoming addicted, his doctor can explain that addiction among drug abusers is a psychological dependence on a drug. That's different from people with cancer who need drugs to relieve physical pain. With long-term use of an opioid pain reliever, a person can become physically dependent, which means that the drugs should not be stopped abruptly, but tapered down slowly.

## Glossary

chronic Long-term, lasting months or years.

**genetic predisposition** Having a higher likelihood of developing a certain illness or condition based on your unique DNA (genetic material).

**neuropathic pain** Pain resulting from damage to nerves or nerve endings due to illness, accident, or medical treatment.

**occupational therapist** A health care professional who helps people improve their ability to perform tasks at home and at work. They work with individuals who experience physically disabling conditions such as neuropathy who need to improve their basic motor functions or compensate for loss of function.

**peripheral neuropathy** Damage to the nerves outside the brain and spinal cord, resulting in pain, tingling, burning, numbness, and/or other sensations.

**physiatrist** A doctor who specializes in physical rehabilitation. Many physiatrists also specialize in treatment of neuropathic pain.

**physical therapist** A health care professional concerned with the prevention and management of movement disorders caused by injuries or disease.

**shingles** A painful infection of the nerves caused by the varicella-zoster virus, which also causes chicken pox.

### Resources

#### Cancer Care

1-800-813-HOPE (1-800-813-4673) www.cancercare.org

### American Academy of Pain Management

1-209-533-9744 www.aapainmanage.org/info/Patients.php

#### **American Cancer Society**

1-800-227-2345 www.cancer.org

#### **American Pain Foundation**

1-888-615-7246 www.painfoundation.org

#### **National Cancer Institute**

Cancer Information Service 1-800-422-6237 www.cancer.gov

### **People Living With Cancer**

(Patient website of the American Society of Clinical Oncology) www.plwc.org

### **The Wellness Community**

1-888-793-9355 www.thewellnesscommunity.org

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The information presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

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## rom the moment of diagnosis, let the hope begin.

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If we can help you and your family, please call us at 1-800-813-HOPE (4673) or visit www.cancercare.org.







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