Understanding Peripheral Neuropathy

CANCERCARE CONNECT® BOOKLET SERIES





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TABLE OF CONTENTS

Introduction	2
Treating Peripheral Neuropathy	3
Tips and Guidance	4
Treatment Side Effects	8
General Side Effects	10
The Role of Pharmacists in Your Cancer Treatment Journey	12
Communicating With Your Health Care Team	15
CancerCare's Free Support Services and Programs	17
Frequently Asked Questions	18
Pasauraes	21

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Cancer treatments can cause peripheral neuropathy, a condition in which nerves that send signals from the brain and spinal cord to other parts of the body are damaged.

Talk to your health care team right away if you experience any of the symptoms of peripheral neuropathy, which include:

- 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 pain
- · Hearing loss
- Problems with balance with cancer or other conditions.



Treating Peripheral Neuropathy

In people with cancer, peripheral neuropathy is usually caused by damage to nerves from surgery, radiation treatment and/or chemotherapy. It can also be caused by a tumor pressing on or penetrating a nerve. The factors that impact the degree to which someone experiences peripheral neuropathy include:

- The type of chemotherapy drug or combination of drugs used
- The chemotherapy dosage
- The way the chemotherapy is delivered: intravenously (into a vein) or subcutaneously (under the skin)
- · The overall length of the treatment regimen
- The presence of contributing factors, such as diabetes or vitamin deficiencies

For mild symptoms, over-the-counter pain relievers such as acetaminophen (Tylenol) and ibuprofen (Motrin)) may be adequate.

Prescription medications used to relieve the pain of peripheral neuropathy include:

- Antidepressant medications. Doses prescribed for the treatment of neuropathic pain are often smaller than the doses typically used to treat depression.
- Anticonvulsants. Anticonvulsants alone or in combination with antidepressant medications can be helpful in treating neuropathic pain.
- Patches or creams. Patches or creams can be applied directly to the affected site.
- **Steroids.** Steroid medications are sometimes used in the short term to relieve severe neuropathic pain until a long-term treatment plan is in place.
- **Opioids.** Opioids are often used in combination with other medications to manage severe neuropathic pain.

If you are currently receiving chemotherapy, your doctor may lower the dose of the drug, as long as it does not make the treatment less effective.

In addition, acupuncture or physical, occupational and relaxation therapy can be effective for neuropathic pain.

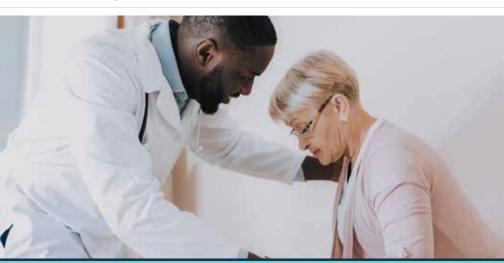
Tips and Guidance

Symptoms of peripheral neuropathy may decrease over time. But it can take one or two years for the symptoms to go away completely, and some people may experience long-term symptoms.

There are a number of steps you can take to help manage and cope with this condition.

- Stay ahead of your pain. Take prescribed and over-the-counter pain medication early in the day, and/or before symptoms become severe. The pain medication can often work more effectively this way.
- Pay attention to your feet.
 - Set up areas in your home where you can sit to perform daily activities you may normally perform when standing up. Such activities include getting ready for the day and prepping meals.
 - Consider "rocker bottom" shoes. This type of shoe is characterized by a thicker sole and a rounded heel, which allows the foot to roll while walking, which can take some of the pressure off of your feet.
 - You can ask a member of your health care team if orthotics (customized foot supports) compression socks and/or a foot massage device are right for you.

- Buy household items with a wide grip. If your hands feel clumsy or weak, consider buying kitchen knives, hammers and other household tools that have a wide grip. This prevents the hand from gripping too tightly, and can prevent discomfort.
 On a related note, take extra care when handling hot, sharp or dangerous objects.
- **Give your hands a rest.** If your hands are affected by neuropathy and you do a lot of work on a computer, consider using voice recognition software. As an alternative to physically typing on a keyboard, you simply talk to the computer (or other device) and your words appear on the screen.
- Avoid alcoholic drinks. Even a glass or two of wine or beer can
 affect your nerves, especially if the nerves have been exposed
 to chemotherapy.
- **Do not smoke.** Studies have shown smoking can increase the pain of peripheral neuropathy.
- Consider a physical therapy evaluation. If you have problems
 with balance, talk to a member of your health care team about
 a physical therapy evaluation. The evaluation will result in
 recommendations which can include the use of assistive
 devices such as canes, walkers with seated benches and
 bathing chairs.



Additionally, as peripheral neuropathy can cause muscle weakness and balance issues that can lead to falls, it's important to ensure your home is as safe as possible:

- Install handrails on stairs and in the bathtub or shower.
- · Use nonslip mats in your bathtub or shower.
- Use an adhesive on the underside corners of large area rugs to keep them secured to the floor.
- · Remove smaller loose rugs and mats.
- Clear your walkways and stairs of anything you could trip over, such as newspapers, shoes, books, decorative items and electrical cords.
- Move small pieces of furniture and decorative items away from high-traffic areas. If you have tables or other furniture with sharp edges, consider applying rubber corner guards for protection.
- Don't walk around the house barefoot or in slippers, stockings or socks. Instead, wear flat shoes with rubber soles.
- Make sure your home is well-lighted. Turn on the lights whenever you are in, or passing through, a room or hallway. Use nightlights to light hallways or rooms during the nighttime.
- Keep a flashlight with functioning batteries next to your bed.
- Turn on your outside lights if you are going out when it's dusk or dark.



The Importance of Clinical Trials

Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things that you should know:

- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial, including any possible side effects
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.

Treatment Side Effects

Cancer treatments can cause side effects other than peripheral neuropathy. It's important that you report any side effects that you experience to your health care team so they can help you manage them. Report them right away—don't wait for your next appointment. Doing so will improve your quality of life and allow you to stick with your treatment plan. It's important to remember that not all people experience all side effects, and people may experience side effects not listed here.

Chemotherapy

The side effects specific to chemotherapy depend on the type and dose of drugs given and the length of time they are used. They can include the following:

- Hair loss. Depending on the treatment, hair loss may start
 anywhere from one to three weeks after the first chemotherapy
 session. Hair usually starts to grow back after the end of
 treatment. It may have a different texture or color, but these
 changes are usually temporary. Specially-designed scalp-cooling
 caps worn during chemotherapy infusions can reduce hair loss.
- Low white blood cell counts. Chemotherapy may lead to low white blood cell counts, a condition called neutropenia. White blood cells play a key role in fighting infection. Your doctor can prescribe medication designed to help increase white blood cell counts. If you develop a fever (a sign of infection), let your health care team know immediately so you can get proper treatment.

- Mouth sores (mucositis). Your doctor may recommend treatments such as:
 - ✓ Coating agents. These medications coat the entire lining
 of your mouth, forming a film to protect the sores and
 minimize pain.
 - ✓ Topical painkillers. These are medications that can be applied directly to your mouth sores.
 - ✓ Over-the-counter treatments. These include rinsing with baking soda, salt water, or using "magic mouthwash," a term given to a solution to treat mouth sores. Magic mouthwash usually contains at least three of these ingredients: an antibiotic, an antihistamine, an antifungal, a corticosteroid and/or an antacid.

Chemotherapy can also cause changes in the way food and liquids taste, including an unpleasant metallic taste in the mouth. Many people find switching to plastic utensils helps. It may also help to avoid eating or drinking anything that comes in a can and to use enamel-coated pots and pans for food preparation.

Radiation Therapy

Changes to the skin are the most common side effects of external radiation therapy; those changes can include dryness, swelling, peeling, redness and blistering. If a reaction occurs, contact your health care team so an appropriate treatment can be prescribed. It's especially important to contact your health care team if there is any open skin or painful areas, as this could indicate an infection. Infections can be treated with an oral antibiotic or topical antibiotic cream.

Side effects of internal radiation (brachytherapy) can include swelling, bruising, bleeding and pain at the spot where the radiation was delivered. It can also lead to short-term urinary symptoms, including incontinence or pain when urinating.

General Side Effects

Some side effects may occur across treatment approaches. This section provides tips and guidance on how to manage these side effects should they occur.

Managing Digestive Tract Symptoms

Nausea and vomiting

- Avoid food with strong odors, as well as overly sweet, greasy, fried or highly seasoned food.
- Eat meals that are chilled, which often makes food more easily tolerated.
- Nibble on dry crackers or toast. These bland foods are easy on the stomach.
- Having something in your stomach when you take medication may help ease nausea.

Diarrhea

- Drink plenty of water. Ask your doctor about using drinks, such as Gatorade, which provide electrolytes. Electrolytes are body salts that must stay in balance for cells to work properly.
- Over-the-counter medicines such as loperamide (Imodium A-D) and prescription drugs are available for diarrhea, but should be used only if necessary. If the diarrhea is bad enough that you need medicine, discuss it with your doctor or nurse.

- Choose fiber-dense foods such as whole grains, fruits and vegetables, all of which help form stools.
- Avoid food high in refined sugar and those sweetened with sugar alcohols, such as sorbitol and mannitol.

Loss of appetite

- Eating small meals throughout the day is an easy way to take in more protein and calories, which will help maintain your weight.
- To keep from feeling full early, avoid liquids with meals or take only small sips (unless you need liquids to help swallow). Drink most of your liquids between meals.
- Keep high-calorie, high-protein snacks on hand, such as hard-boiled eggs, peanut butter, cheese, granola bars, liquid nutritional supplements, nuts, canned tuna or trail mix.
- If you are struggling to maintain your appetite, talk to your health care team about whether appetite-building medication could be right for you.

Constipation

- As hydration is important to avoid constipation, make sure to drink plenty of fluids. Also, limit your intake of caffeine and alcoholic beverages, as they can cause dehydration.
- Include foods high in fiber in your daily diet, such as fruit
 (especially pears and prunes), vegetables, and cereals. If your
 health care team approves, you may want to add synthetic fiber
 to your diet, such as Metamucil, Citrucel or FiberCon.
- Be as physically active as you can, after checking with your health care team on the level of physical activity that is right for you.
- If your doctor has prescribed a "bowel regimen," make sure to follow it exactly.

Managing Fatigue

Fatigue (extreme tiredness not helped by sleep) is one of the most common side effects of many cancer treatments. If you are taking a medication, your doctor may lower the dose of the drug, as long as it does not make the treatment less effective. If you are experiencing fatigue, talk to your doctor about whether taking a smaller dose is right for you.

There are a number of other tips for reducing fatigue:

- Take several short naps or breaks during the day.
- Take short walks or do some light exercise, if possible.
- Try easier or shorter versions of the activities you enjoy.
- Ask your family or friends to help you with tasks you find difficult or tiring.
- Save your energy for things you find most important.

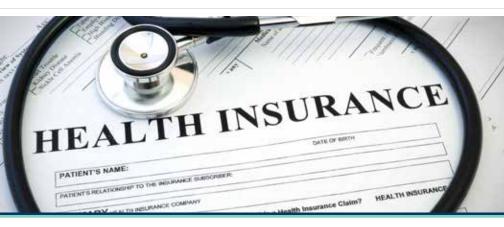
Fatigue can be a symptom of other illnesses, such as anemia, diabetes, thyroid problems, heart disease, rheumatoid arthritis and depression. So be sure to ask your doctor if they think any of these conditions may be contributing to your fatigue.

The Role of Pharmacists in Your Cancer Treatment Journey

Pharmacists are highly accessible members of the health care community. While pharmacists are often employed by independent or chain drug stores, they also work in clinics, hospitals and specialty pharmacies (organizations which manage the dispensing, reimbursement, case management and other services specific to medications for complex or chronic conditions).

Regardless of the type of medicine that a doctor prescribes, pharmacists help people by:

- Explaining how the medication works. Your doctor or another member of your health care team may have reviewed the ins-and-outs of the medication when you received your prescription, but hearing the information more than once is helpful—especially at what can be a stressful time.
- Reinforcing how the medication is to be taken. For example, some medications should be taken with meals; others should be taken on an empty stomach. If the medication is self-administered via an injection, the pharmacist can explain the proper injection technique.
- Reviewing possible side effects. This information is provided in the Package Insert (PI) that accompanies the medication, but it can be valuable to hear it explained in everyday language. The pharmacist can also monitor any side effects you may experience and offer guidance (in collaboration with your health care team) on possible ways to relieve the symptoms these side effects may cause.
- Explaining what your insurance covers. An insurer may require that the generic version of the drug be dispensed, if one exists. Your pharmacist can help explain any differences between the original drug and the covered drug, including any out-of-pocket cost implications.



- Ensuring patients take their medication as prescribed.

 Pharmacists can provide tips to help you take your medication as prescribed, such as using a pill sorter to stay organized, and signing up for automated refill reminder calls or text messages from the pharmacy. They may also suggest you download a medication reminder app for use on your smart phone or tablet. Many of these apps are available for free or at a small cost.
- Recommending financial resources. There are a number of financial aid organizations and patient assistance programs available to help patients with their out-of-pocket expenses.
 Your pharmacist can be a good source of information about these resources.



Communicating With Your Health Care Team

As you manage your cancer, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and the members of your health care team, including doctors, nurses, nurse practitioners, physician assistants, dietitians, social workers, pharmacists and patient navigators.

Here are some tips for improving communication with your health care team:

Start a health care journal. Having a health care journal or notebook (either on paper or in a digital format) will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Keep a list of your current medication, including frequency and dose taken, and a diary of your daily experiences with cancer and treatment. You can separate your journal or notebook into different sections to help keep it organized.

Prepare a list of questions. Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, you should ask your most important questions first, and be as specific as possible.

Bring someone with you to your appointments or have them be present during telehealth sessions. Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support during your appointments. The other person can serve as a second set of ears. They may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

Write down your doctor's answers. Taking notes will help you remember your doctor's responses, advice, and instructions. If you cannot write down the answers, ask the person who accompanies you to take notes for you. If you have a mobile device, like a tablet or smartphone, ask if you can use it to take notes. Writing notes will help you review the information later.

Record your visit if your doctor allows it. Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.

Incorporate other health care professionals into your team.

Your medical oncologist is an essential member of your health care team, but there are other health care professionals who can help you manage your diagnosis and treatment:

- Your primary care physician should be kept updated about your cancer treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking. Have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.

- Make sure your oncologist knows of any other medical conditions you have or any pain you are experiencing, so that they can consult with your primary care physician or your specialist if needed.
- Ask your oncologist to send a summary of your visits to your primary care physician and all doctors involved in your care.

Remember, there is no such thing as over-communication.

Cancer *Care's* Free Support Services and Programs

It can be very difficult to receive a diagnosis of cancer, and adjusting to the necessary changes in your life can be challenging.

Cancer Care® can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how Cancer Care helps, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

You will likely also build your own personal support network composed of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store, or ask a friend who's a good listener to come over for a chat.

MORE ABOUT PERIPHERAL NEUROPATHY

Frequently Asked Questions

Q. Can you share tips for dealing with peripheral neuropathy in cold weather?

A. Peripheral neuropathy can be particularly challenging in cold weather. Prolonged exposure to cold causes the body to slow blood circulation to the hands and feet in an effort to preserve the body's core temperature. The reduced blood flow can intensify neuropathy symptoms and potentially cause further damage to already affected peripheral nerves.

Here are some cold-weather tips to lessen the pain and lower your risk of further nerve damage:

- · Wear warm, dry clothing.
- Protect your hands and feet by wearing thick socks and thick mittens or gloves.
- Take intermittent breaks from the cold to reduce your exposure to extreme temperatures.
- Limit or avoid caffeine before an outing as it can temporarily cause blood vessels to narrow.
- Incorporate exercise into your routine to improve overall circulation.



Q. I've been experiencing neuropathy along with other types of pain. What information should I discuss with my health care team?

A. It's important that you report any pain or discomfort you experience to your health care team right away. Following are key points to discuss with a member of your health care team:

- Where the pain occurs. Is the pain in one or multiple locations in your body?
- The nature of the pain. Is it dull, sharp, stabbing, burning or pinching?
- When the pain occurs. Was there a specific event that preceded the occurrence of the pain?
- How long it has lasted. When did it first occur?
- How strong it is. How would you rate the strength of the pain on a scale of 1 to 10, with 1 being the least amount of pain and 10 being the most intense?
- Whether anything makes the pain worse. Does standing or sitting make it hurt more? Is it worse at night and better during the day?
- Whether anything makes the pain better. Do you feel better if you apply ice or heat to the area? Does it help if you lie down or walk around? Do over-the-counter medications help?
- Whether the pain is "breakthrough." Is your pain normally well-controlled but has now flared, in spite of the medication you are taking?
- How the pain is affecting your everyday life. Is your sleep or appetite affected? Are you able to perform your normal activities?

It may be helpful to keep a "pain journal" with the above information, so that you have specific details to share when you talk to your healthcare team about your pain.

Q. What is biofeedback therapy and can it help with neuropathic pain?

A. Biofeedback therapy can be used to treat chronic pain, including the pain associated with peripheral neuropathy. This type of therapy uses technology to measure certain involuntary body functions, such as heartbeat, blood pressure, and muscle tension. It also identifies how changes (physical responses) in these functions affect the person's level of pain. A trained therapist then teaches the use of relaxation techniques to control the physical responses, which can lead to the elimination or reduction of pain.

Relaxation techniques that may be trained include:

- · Deep breathing exercises
- Guided imagery, in which you concentrate on a place or situation that you find peaceful
- Alternately tightening and relaxing different muscle groups
- Mindfulness meditation, designed to focus your thoughts while allowing you to let go of negative emotions

Ask a member of your health care team if biofeedback therapy could be right for you.



Resources

CancerCare®

800-813-HOPE (800-813-4673)

www.cancercare.org

American Cancer Society

800-227-2345

www.cancer.org

Cancer.Net

Patient information from the American Society of Clinical Oncology 888-651-3038

www.cancer.net

National Cancer Institute

800-422-6237

www.cancer.gov

Cancer Support Community

888-793-9355

www.cancersupportcommunity.org

National Coalition for Cancer Survivorship

877-622-7937

www.canceradvocacy.org

Medicine Assistance Tool

www.medicineassistancetool.org

CLINICAL TRIALS WEBSITES

EmergingMed

www.emergingmed.com

National Cancer Institute

www.cancer.gov

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WWW.CANCERCARE.ORG 800-813-HOPE (4673)